

Quality of Life:

The Evaluation and Development of Services for

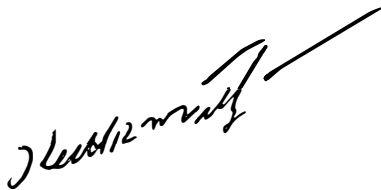
People with Intellectual Disability

Master of Psychology

Dept of Psychology

September 1997

I certify that this thesis contains no material which has been accepted for the award of any other degree or graduate diploma in any other university, and that to the best of my knowledge and belief this thesis contains no copy or paraphrase of material previously published or written by another person, except where due reference is made in the text of the thesis.

A handwritten signature in black ink, appearing to read 'Keith R. McVilly', with a long horizontal stroke extending to the right.

Keith R. McVilly B.A., Grad. Dip. Psy., MAPS
September 1997

Acknowledgments

I wish to express my gratitude for the advice and encouragement given to me by my supervisor, Rosanne Rawlinson. Without her support (and extreme tolerance) this project may never have been completed.

Sincere thanks also to Dr John Davidson, Dr Ted Thompson, and others in the Department of Psychology, University of Tasmania, for their invaluable advice.

To those who responded to questionnaires, I am deeply indebted. I wish to acknowledge Jim Woodworth and the staff at Disability Services, without whose support and encouragement this project would not have been possible. Also, I wish to acknowledge clients and staff of Family Based Care and members of the Tasmania Fire Service who assisted with data collection.

I offer thanks to my family, friends and colleagues, especially those at Vocational Rehabilitation Services, for their support.

Abstract

In this review issues and methodologies pertaining to the promotion and assessment of the quality of life (QOL) experienced by people with Intellectual Disability (ID) are evaluated in light of research findings for people without ID. QOL is discussed in terms of a multidimensional and dynamic construct used as an indicator of psychological and physiological wellbeing. Objective and subjective components of QOL are reviewed, together with social and psychological factors. Various approaches to the assessment of QOL, such as the examination of people's physical location and their opportunity to acquire and apply skills for independent living are considered, together with process-centered and outcome-centered approaches to evaluation. The influence of Social Role Valorization/Normalization and processes such as deinstitutionalisation and community integration are discussed. Difficulties, such as limited receptive and expressive communication skills, encountered when eliciting the perspective of people with ID are considered. So too, difficulties inherent in the use of proxy-based respondents are discussed. It is proposed that future research should address the question of proxy-subject concurrence, including the systematic evaluation of demographic and psychological factors that may affect proxy-subject agreement concerning QOL assessment.

CONTENTS

A Literature Review

Quality of Life : Evaluating Services for People with Intellectual Disability

A Rational for QOL Research in the Field of Intellectual Disability	p. 2
Dimensions of QOL	p. 4
Process Evaluation and Outcome Evaluation	p. 7
Deinstitutionalization and Community Integration	p. 9
The Measurement of Objective QOL	p. 12
The Measurement of Subjective QOL	p. 15
Accessing QOL for People with Intellectual Disability	p. 20
Proxy Respondents and the Measurement of QOL	p. 23
Directions for Future Research	p. 29
References	p. 31

A Journal Article p. 40

Concurrence between subject and proxy ratings of QOL for people with and without Intellectual Disability: the role of mediating factors

Appendices p. 78

Quality Of Life:
Evaluating Services
for People with Intellectual Disability

by
Keith R. McVilly B.A., Grad. Dip. Psy., MAPS

A literature review submitted as partial requirement for the degree
Master of Psychology (Clinical)
in the Department of Psychology, University of Tasmania at Hobart,
September, 1997.

A Rationale for QOL Research in the Field of Intellectual Disability

Quality of life (QOL) is a global concept used to articulate aspects of an individual's state of physical, social, emotional and spiritual well being. QOL is defined in terms of both cultural standards and norms and with reference to the desires, needs, experiences and aspirations of the individual (Donegan & Potts, 1988). Historically, QOL has emerged from the disciplines of sociology and social psychology. It has been used to make empirical statements concerning community life, urban development and social progress (Thorndike, 1939), and has been applied in areas as diverse as gerontology (Edwards & Klemmack, 1973; Spreitzer & Snyder, 1974; Parmenter, 1992), mental illness (Lehman, 1983), chronic illness (Gill, 1984), closed head injury (Klonoff, Snow & Costa, 1986), mobility (Hirst, 1989) and intensive care (Ridley & Wallace, 1990). Shye (1989) proposes that QOL is a mechanism for social change and to this end suggests three methodological approaches. The 'grass roots approach' emphasises ethnographic observational techniques in naturalistic settings. The 'means to quality of life approach' stresses the assessment of systems that affect people, and the 'direct facet definitional approach' focuses on direct questioning of people with regard to their feelings and understanding of aspects of their environment. Shye concludes that the complexity of QOL demands all three approaches be applied in a systematic manner.

In the field of intellectual disability (ID), QOL has emerged as an important area of research (Rowitz, 1989). Schallock (1989) predicted that QOL would replace deinstitutionalisation, normalisation and community adjustment as the pre-eminent issue of the 1990s in the field of ID. The necessity to evaluate QOL is twofold.

First, when developing services, there is a need to establish facets of life that service-

users value, so that their needs can be more effectively addressed. Second, when reviewing services, it is necessary to objectively quantify QOL outcomes in order to justify public expenditure on specific services. In an economic climate of non-finite demands and finite economic resources, an ideological commitment to deinstitutionalisation and community integration is not a sufficient argument for securing long-term service provision. Some authors have suggested that failure to objectively evaluate deinstitutionalisation in terms of improvements to the quality of life experienced by people with ID, will hazard a return to the more traditional large-scale institutional based support systems (Zigler & Balla, 1977; Eyman, Demaine & Lei, 1979). Such a failure may result in the loss of the many gains that have been realised with the development of small scale-community based services (Tuckey & Tuckey, 1981; Wing, 1989). Furthermore, in recognition of the need to establish standards against which services can be evaluated, the impetus for QOL research in the field of ID has been embedded in legislation such as the Commonwealth Disability Services Act (Commonwealth of Australia, 1986) and complementary legislation in all state jurisdictions throughout Australia. Such legislation prescribes principles, objectives and standards that require funded agencies to assess their services in terms of the degree to which they actively promote quality of life for people with disabilities.

The promotion of QOL is widely recognised as a critical issue in the development, provision and evaluation of services for people with disabilities. Therefore this review examines the various dimensions of QOL, and evaluates a number of theoretical approaches and specific methodologies that have been developed to monitor and assess the degree to which agencies promote QOL for service users. It also examines the difficulties accessing the perspective of people with limited

receptive and/or expressive cognitive abilities in relation to their own QOL, as well as the problems associated the use of proxy respondents. The review concludes with some proposed directions for future research.

Dimensions of QOL

The composition of QOL remains controversial and there is little agreement in the literature concerning its precise definition. However, there is general concurrence that QOL is a multidimensional construct, comprised of both objective and subjective dimensions. Most authors agree that any consideration of these dimensions depends on the assessment of both organisational processes and outcomes for people serviced by the organisation. Furthermore, some indication of the relative importance of particular issues to these individuals, and their ratings of satisfaction are essential (Cummins, 1993).

The objective indicators endorsed by most authors who assess the various dimensions of QOL include living conditions, neighborhoods, educational opportunities and income. Subjective indicators include patterns of personal relationships, expectations, attitudes and behaviours (Brown, Bayer & McFarlane, 1988.). The objective-subjective dichotomy has been developed on the premise that objective and subjective variables are tapping significantly different bodies of data. This position is supported by the findings of Lewis and Ryan (1986) who observed that there was little relationship between objective indicators and subjective indicators of QOL. The objective-subjective dichotomy is recognised in the literature as the hallmark of any valid measure of QOL in the area of ID (Barlow & Kirby, 1991; Brown & Bayer 1991; Cummins, 1993). Parmenter (1992) proposes an

alternative dichotomy, based on of social and psychological indicators. Here, social indicators include income, marital status, race, sex and community locality.

Psychological indicators include perceptions of physical and material wellbeing, relationships with others and indications of the degree to which an individual feels fulfilled. Generally, the literature supports the use of both objective and subjective factors. Nevertheless, the use of subjective factors has been criticized. For example, Parmenter (1992) argues that subjective factors may be prone to variation across time and between subjects, and that they may be susceptible to examiner bias.

Furthermore, Parmenter argues that subjective indicators are difficult to compare between groups, presenting problems for replication.

In an analysis of the quality of life in Australia, Headey (1981) operationalises QOL in terms of individual aspirations, expectations and perceptions of equity of treatment in various domains of daily life. Headey structures his analysis by considering a variety of social issues and gains from his respondents both a cognitive evaluation ('what do you think about ...?') and an emotional evaluation ('what do you feel about ...?') of each issue. Similarly, Groeland (1990) identifies three critical domains as the basis of effective QOL research. These domains are described by the author as the objective (social), judgmental (cognitive) and affective (emotional) domains.

Chun Yu, Jupp and Taylor (1996) argue that QOL is a dynamic concept. That is to suggest, aspects of an individual's life can vary in relative importance across time as a result of changes to both objective factors and the individual's personal frame of reference. Current experiences and the salience of memories of previous experience may account for this changing frame of reference. These findings are consistent with

those of Headey (1981), who notes that both specific and general indicators of wellbeing are of varying importance to individuals according to their stage of development. Similarly, Borthwick-Duffy (1990) concludes that it is reasonable to assume the same general dimensions of life quality are meaningful for all levels of intelligence, but the relevance of specific criteria used to define and measure those dimensions is likely to differ across disabilities and handicaps. It is this variability in the salience of issues included in assessments of QOL that Johnston (1988) identifies as the major obstacle to development of a comprehensive quality of life index. This author argues that researchers need to focus on changes across time in factors that affect QOL, rather than attempting to measure QOL itself. Johnston stresses that in any assessment of QOL, the omission of perceptual or attitudinal data is a serious deficit. This view is consistent with Flanagan (1978), who asserts that researchers need to develop methodologies which take into account the relative importance that individuals attach to various aspects of life.

Addressing the complexity of QOL, Daniel and Vining (1983) and Eyles (1990) stress the importance of the ethnographic approach to research. They propose five dimensions for QOL assessment, each of varying utility according to circumstances. These dimensions include ecology of the environment (naturalness of features), aesthetics (harmony with surroundings), psychophysical aspects (stimulation for the individual), psychological factors (opportunities for development) and phenomenological aspects (the interaction of the person and the environment). Of particular interest is Eyles' (1990) distinction between the quality of the environment and the quality of life, and likewise between the measured and the perceived quality of each. This approach is consistent with Headey (1981) who reports that studies show only weak linkages between people's objective social conditions and their

subjective satisfaction. Similarly, Brown et al. (1988) note "Quality of Life includes, but is not equivalent to people's life satisfaction, their happiness or their sense of control" (p.112). In addition to the multi-dimensional construction of QOL, there is evidence in the literature of a dichotomous approach to QOL assessment methodologies. These two complementary but distinct methodologies are operationalised in terms of process-centered and outcome-centered evaluations.

Process Evaluation and Outcome Evaluation

A review of QOL research reveals an important distinction between process evaluation and outcome evaluation. Process evaluation generally focuses on the day-to-day operation of services and how services interact with clients. Process evaluation is primarily concerned with organisational policies and procedures. Outcome evaluation is concerned with what services actually achieve for their clients (Davey & Pitfield-Smith, 1992). The important distinction between process and outcome evaluation can be seen in findings that suggest quality care is a critical component of effective service provision, but does not necessarily guarantee quality life experiences (Riddle & Riddle, 1982). As Bothwick-Duffy (1990) observes, "The documentation associated with meeting standards and regulations, the primary focus of process evaluation, often becomes a barrier to the happiness of persons who live in those facilities that are overly concerned with certification." (p. 180).

Process evaluation may be conducted by using tools such the Program Analysis of Service Systems Implementation of Normalization Goals or PASSING (Wolfensberger & Thomas, 1983). It assesses physical settings and organisational structures, together with the language and symbols that services adopt. Applying

such an evaluation espouses the principle that policies, procedures and environmental features necessarily promote quality of life. The benefits of approaches such as PASSING are largely administrative. They provide readily assessable standards for the purposes of holding services accountable, especially to funding bodies.

However, despite these advantages, Bellamy, Newton, LeBaron and Horner (1990) cite three drawbacks to process evaluation. First, the variables provide only an indirect index of QOL. They do not consider the impressions, reactions and responses of clients to the service delivery system. Second, process evaluations generally assume all clients to be the same. They fail to take into account specific environmental features that are important to individuals. Third, the variables are program-centered, not client-centered. Their application may unwittingly shift the organisational focus away from the needs of individuals.

In contrast to process evaluation, outcome evaluation generally focuses on the development of client skills and adaptive behaviours. These variables are evaluated according to the degree to which change is evident as a result of involvement in specific programmes or movement between programmes. Outcome evaluation also targets lifestyle indicators, such as friendship networks and variety in educational or leisure options (Bonanno, Gibbs & Twardzicki, 1982; Edgerton, 1984; Landesman, 1986).

O'Brien (1984), building on the work of Nirje (1970) and Wolfensberger (1972), attempts to bridge the gap between Normalisation-centered process evaluation and outcome evaluation. He defines five organisational accomplishments said to promote the quality of life of service users. These accomplishments are measured in terms of the degree to which clients are present in the community, actively

participate in mainstream activities, exercise choice, have access to opportunities to display their competence and, finally, have their rights and dignity respected.

Valid and reliable indicators for *both* process and outcome evaluation of QOL are vital for the adequate assessment of QOL. If the QOL measurement is not accurate, the system is in danger of failure to improve over time, and this failure may not be detected (Bellamy, et al. 1990). Alternatively, and even more seriously, the system may in fact deteriorate over time and the subsequent decline in the QOL of service users may go undetected (Conroy & Feinstein, 1990). These considerations are of particular importance when monitoring services for people with severe and profound disabilities, where clients may be limited in their ability to directly report variations in their QOL, and current instrumentation is insufficient to detect such variations. This problem is one of the most critical issues surrounding the deinstitutionalisation of services and the advancement of community integration for people with ID.

Deinstitutionalisation and Community Integration

Deinstitutionalisation (DI) is predominantly a political-economic policy involving the relocation of people from large-scale service systems in isolated settings, to small-scale service systems in the community. It also encompasses the restructuring of policies and procedures to more effectively address the needs of individuals, as opposed to organisations. Community Integration (CI) is a social policy, linked to deinstitutionalisation. It incorporates an ideological stance promoting the pursuit of opportunities for people with ID to access generic services and to participate in social activities with people who do not have disabilities.

Both DI and CI have been pursued as the most effective means of implementing Normalisation and Social Role Valorisation (Nirje, 1985; Wolfensberger, 1983). Hence DI and CI are promoted as the most effective means of instigating positive changes in the quality of life experienced by people with disabilities (Hemming, Lavender & Pill, 1981; Emerson, 1985; Sullivan, Vitello & Foster, 1988). The philosophy of Normalisation was first advanced by Banks-Mikkelsen during the 1950s (Banks-Mikkelsen, 1969). Normalisation has since been defined as “a means of making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of mainstream society” (Nirje, 1970; p.62). This philosophical impetus is arguably the single most influential concept in the development and implementation of services for people with disabilities. It was further elaborated by Wolfensberger (1972) as the utilisation of means which are culturally normative in order to establish and maintain personal behaviours and characteristics which are as culturally normative as possible. During the 1980s it was Wolfensberger who reconceptualised Normalisation in terms of Social Role Valorisation (SRV). SRV focuses the responsibility for change in the lives of devalued individuals such as people with ID, on environmental factors, including services and service providers, rather than on the individual with a disability. SRV is operationalised as a means of evaluating service quality through the Programme Analysis of Service Systems Implementation of Normalisation Goals, or PASSING Programme (Wolfensberger & Thomas, 1983).

Some authors propose that the implementation of SRV through DI and CI enhance the quality of life experienced by people with disabilities. This proposition is supported by evidence that physical and social integration enables people with disabilities to develop the autonomy, choice, freedom, respect and dignity afforded to

and valued by other members of the community (Vitello & Soskin, 1985). DI and CI have also been used to redress the effects of institutionalization; the specific behavioural patterns of residents in large institutions, that are distinct from the residents' primary clinical condition (Standon, 1954; Barton, 1959; Wing, 1962; Szasz, 1973). Institutional patterns of behaviour are severely debilitating. They include unquestioning compliance with rules, an absence of assertive action, a lack of spontaneity, flexibility and inability to adapt to changing social demands, egocentric preoccupation with bodily functions, as well as an inability to establish relationships (Goffman, 1962). Any assessment of QOL should therefore consider the presence of these behaviours, and the degree to which they impede a person's participation in the wider community.

Service providers generally assume that DI and CI have a positive effect on the quality of life experienced by people with disabilities. However, Scheerenberger (1974) observed that it is possible for community residences to become as dehumanized as large institutions has questioned this assumption. Butler and Bjannes (1978) found that community facilities, from small family-style units to large units, could replicate some of the worst aspects of traditional institutions. Furthermore, Sandler and Thurman (1981) conclude that the literature provides limited support for the view that people with ID benefit from placement in the community as opposed to traditional institutional settings. Similarly, Lakin, Bruininks and Sigford (1981) observe "the social status and personal power of mentally retarded persons remain unchanged, even though their place of residence may have changed" (p.391). The consensus in the literature is that physical relocation does not automatically have a positive effect on the quality of life of people with disabilities, and deinstitutionalisation requires more than just placing a

client into a community-based program (Novak & Heal 1980; Estroff, 1981; Felton & Shinn, 1981; Bachrach & Lamb, 1982; Hogg & Mittler, 1987). Therefore, where outcome-focused evaluations are used, physical relocation is not in itself a valid indicator of changes in QOL. Where process-focused indicators are used, they should take into consideration policies and procedures, together with practices that promote clients' access to generic services and the development of social relationships. Critics of process-focused evaluation have argued that the primary issue should be the effect service systems have on the individuals they are designed to support (Mesibov, 1976). They argue that positive effects will be most evident in the development of adaptive behaviour and positive social adjustment, which have been generally accepted as de facto indicators of objective QOL.

The Measurement of Objective QOL

Researchers have found that adaptive behaviour and the skills necessary for positive social interaction develop with the implementation of DI and CI (Molony & Taplin, 1988). The development of adaptive behaviour has therefore been accepted as an indicator of improved QOL for people with ID. Research into adaptive behaviour and social adjustment represents an outcome approach, as opposed to a process approach to the evaluation of QOL (Evans, Felce & Hobbs, 1991). Such research is consistent with Mesibov's (1976) call for a focus on the effects that service systems have on the lives of individuals.

Attempts to measure objective outcomes have become increasingly sophisticated. Early studies concerned with DI and CI did not attempt to directly measure variations in QOL. Rather, they focused on whether people remained in the community or were

re-institutionalised (Windle, Stewart & Brown, 1961; McCarver & Craig, 1974; Heal, Sigelman & Switzky, 1978). Subsequent studies investigated factors in the failure of community placement. These studies established that the critical factors contributing to reinstitutionalisation included the incidence of maladaptive behaviour and the presentation of poor social adjustment (Fotheringham, 1970; Fotheringham, Skelton & Haddinott, 1971; Eyeman, O'Conner, Tarjan & Justice, 1972.). In short, the success or failure of community placement as a function of the incidence of maladaptive behaviour, was used as a de facto indicator of QOL, measured primarily in terms of a person's physical location.

A number of researchers have used daily activity patterns as an indicator of QOL (Bjaanes & Butler, 1974; O'Conner 1976; Birenbaum & Re, 1979). Such research has been developed with the understanding that variations in an individual's activities can be directly equated with variations in their quality of life. Research into activity patterns has involved measures of the variety in activities, the degree of independent action exhibited by individuals while engaged in activities, together with the amount of social contact achieved as a result of participation in activities (Diller, Fordyce, Jacobs & Brown, 1982). The methodologies employed include participant observation techniques (Sullivan, Vitello & Foster, 1988) and respondent-based ratings provided by support staff (Raynes, Sumpton & Pettipher, 1986). Researchers have also focused on the acquisition of adaptive behaviour (Novak & Heal 1980; Craig & McCarver 1984; Rotegard, Bruininks, Holman & Lakin 1985). This approach has been adopted with an understanding that "a comprehensive framework for evaluating a person's quality of life requires a grounded, qualitative assessment of his or her actual social performance in a particular social settings" (Sullivan et al.,

1988, p.76). It represents a significant advance from the success/failure criteria of earlier DI and CI studies.

Generally, the literature demonstrates that significant improvements in adaptive functioning and social adjustment arise as a result of transfer from a large institutional environment to a community residential unit, particularly for people with a moderate to severe levels of disability. However Molony and Taplin (1988) maintain that outcomes for people with more profound levels of disability and behaviour disorders are less certain. Research into the development of adaptive behaviour has targeted a range of skill areas including communication, personal care, personal presentation, domestic and community living, fundamental survival skills (Sullivan et al., 1988.). The means of assessing quantitative changes in behaviour and adjustment have ranged from check-lists devised by individual institutions to more standardised instruments such as the Scales of Independent Behaviour (Bruininks, Woodcock, Weatherman & Hill, 1985), the Inventory for Client and Agency Planning (Bruininks, Hill, Weatherman & Woodcock, 1986) and the Vineland Adaptive Behaviour Scale (Sparrow, Balla & Cicchetti, 1984)

The development of adaptive behaviour and social adjustment, and their subsequent effect on the individual's quality of life, can be identified in studies of community placement. Aanes and Moen (1976) found increases in independent functioning, language development and socialisation among people living in group homes.

Thompson and Carey (1980) noted improvement in language development, domestic activity and social skills. In a two-year longitudinal study that followed a group of people who moved from large living units to bungalow-style accommodation, Hemming et al. (1981) noted increases in independent functioning, physical

development, language development, numeracy, domestic skills, the development of self-direction and the expression of self-responsibility. Therefore, it appears that QOL is intrinsically linked to environmental factors providing the individual with opportunities to develop adaptive behaviours and positive social adjustment. These factors permit an increased variety of activities, opportunities to exercise personal autonomy in those activities and, consequently, increased opportunities for social contact.

In any evaluation of QOL it is evident that both process and outcome evaluation are vital components. It is essential to assess both facets, because a one-sided evaluation may result in a failure to address the important interface between an individuals' needs and the service structures that provide them. The emphasis here is on the objective measures of QOL either from a systems or an individual viewpoint. Nevertheless, more recent work in the QOL area suggests an increasing emphasis on assessing subjective indicators of QOL.

The Measurement of Subjective QOL

It is only recently that attempts have been made to directly measure QOL as a construct in its own right, not simply as a by-product of community placement, variations in daily activity patterns, and the acquisition of adaptive behaviours. To this end, Goode (1988) proposes a number of principles for determining the issues relevant to QOL assessment in the field of ID. Goode concludes that quality of life for a person with disabilities comprises of factors that are common to the experience of the wider population. Furthermore, he emphasises that measuring the difference between the individual's expressed needs and expectations, and their experience of

having those needs and expectations met is critical in the assessment process. Goode also advocates a multi-informant method for data collection, incorporating subjective data that include the client perspective. Finally, he notes the importance of cultural, environmental and individual developmental factors.

Brown and Bayer (1991) argue that the issues relevant for understanding a person's quality of life include their living situation, range of available activities including work and leisure options; family, friends and social support; finances and health; self-concept and attitude towards life. An alternative perspective is proposed by Bradley, Caldwell, Brisby, Magee and Whiteside (1992), who highlight six issues for investigation. These issues include physical environment, structured learning opportunities, opportunities for affective modelling, patterns of activity, variety of activity, acceptance by others and opportunity to exercise responsibility. Bradley et al. emphasise the importance of both physical and emotional components to assessment of QOL, including what Brown and Bayer (1991) refer to as 'attitude towards life' and what Bradley et al. refer to as 'perceived acceptance' and the opportunity to exercise responsibility. The primacy of independence can be seen in the comments of a person with a disability who, in response to a survey, stated "...we can have a good quality of life if we have control over our own lives and if we have the help we need to keep that control and independence in our own lives." (Schallock & Begab, 1990, p. 4). Similarly, Barlow and Kirby (1991) and Barlow (1992) identify nine components in the investigation of QOL. These components are the individuals' residential setting, leisure activities, work and occupational pursuits, financial situation, relationships, community functioning, safety, health and self-concept, incorporating locus of control, self-esteem and prevalence of depression. The

authors also seek to address transition issues which are predominantly structural and which relate to organisational supports.

Brown and Bayer (1991), Bradley et al. (1992) and Barlow (1992) provide comprehensive reviews of the issues for assessment, including subjective data. However, they fail to provide for the weighting of the issues according to the perspective of the individual. Their approach to QOL assessment presupposes that all issues are of equal importance to all individuals at all times. This premise is not consistent with the findings of Headey (1988), Taylor and Bogdan (1990) and Borthwick-Duffy (1990), who all conclude that issues vary in their salience to individuals according to the degree of disability, stage of development and expectations based on life experiences and cultural factors.

In the development of the Comprehensive Quality of Life Scale (ComQol), Cummins (1993) addresses the problem of item significance for individual respondents. Specifically, Cummins provides for the individual ranking of both the importance and satisfaction a respondent feels with regard to seven QOL issues, including material things, health, productivity, intimacy, safety, perceived place in the community and emotional well-being. An important feature of Cummins' ComQol is the provision of a number of methods for eliciting responses from people with ID, including the use of facial symbols depicting emotional responses linked to Likert-type scales of varying complexity. Cummins' response formats are designed to elicit responses from people with disabilities whose primary means of communication may be non-verbal. However, considerable difficulties still remain when investigators wish to gauge responses from people with moderate to severe intellectual disability. Results from one evaluation project utilising the Com Qol-ID suggested that the

instrumentation may not be suitable for use with people who have severe intellectual disabilities (R. Rawlinson, personal communication, October 1993).

An important contribution of Cummins' work is that it operationalises seven key issues that may affect the quality of life of most people, regardless of their having a disability or not. However, and most importantly, Cummins' methodology also allows for these issues to be weighted according to the degree of importance individual respondents attach to them. This approach is consistent with earlier work conducted by Headey (1981) that investigated quality of life in the Australian population. According to Headey, researchers using longitudinal study designs have found that adults pass through different stages of development during which their life concerns and levels of psychological wellbeing alter significantly. A further contribution by Headey is his conceptualisation of QOL. For Headey, QOL is represented by individuals' perceptions of the gap between their experience of everyday living and their expressed expectations and aspirations. A similar conceptualisation was adopted by Milbrath (1982) and later by Parmenter (1988), who concur in their view that quality of life is defined in terms of the fulfilment of one's values, goals, aspirations and needs. Headey and others conclude that it is not sufficient to simply gauge individual responses to the environment, but that responses must be considered in the context of personal expectations. Furthermore, this perspective emphasises the importance of outcome evaluation in terms of consumer expectations, in contrast to process evaluation, which emphasises the use of predetermined models of service delivery arising from the philosophical stance of so-called 'experts'.

Several approaches attempt to combine an outcome-based assessment with a philosophical superstructure. For example, O'Brien (1984) proposes five life themes for consideration: choice, competence, respect and dignity, community presence and community participation. Alternatively, Parmenter (1992) concludes that from a symbolic interactionist perspective, an analysis should be structured around individuals' perception of themselves, their responses to relevant ecological domains together with environmental responses towards them, their needs and aspirations. These two approaches can identify aspects of people's lives that will benefit from enhancement or enrichment. However, this view does not identify life spaces which can be readily conceptualised or identified by people with moderate to severe intellectual disability, and subsequently commented upon by the people themselves.

For assessment to maximise input from service users, the issues posed must be communicated in such a way that the person is readily able to conceptualise them and then provide meaningful responses. For that purpose, it is necessary to examine tangible life-spaces, including domestic, occupational and recreational situations. It is also necessary to consider community living situations. The considerations include access to transportation, financial support and advocacy services. Furthermore, personal living factors such as physical and mental health need to be canvassed. The life-space approach is consistent with the model for general service plans proposed by Hudson and Cummins (1991), for use in service delivery to people with disabilities.

Davey and Pitfield-Smith (1992) address the need for a multi-measure approach to the assessment of QOL. They propose the use of a battery of instruments, including a least restrictive treatment model check-list, a staff satisfaction questionnaire, an

observational assessment, staff activity catalogue, a daily activity list, a vocational educational interview, a lifestyle report, a client satisfaction questionnaire, a family satisfaction questionnaire, and a neighborhood relations questionnaire. The authors identify three principal sources of data, including service user responses, direct observations and evaluations by family members and staff. However, they acknowledge the need for further research addressing issues such as the use of augmentative communication techniques for people with severe disabilities, observer bias and the validity of proxy responses.

When designing instruments, researchers need to take into account both objective and subjective data. Where subjective data are involved, internal checks of reliability such as question reversal techniques need to be included. Respondent acquiescence should be taken into account, with response schedules designed to avoid two-choice, yes/no formats. Schedules should ideally provide for a range of expression on any one issue. Furthermore, instrumentation should be sufficiently sophisticated to satisfy psychometric standards, but not to the exclusion of valuable subjective data. Questionnaire formats should be simplified for respondents. Also, it is important to recognise that many family informants and support staff may experience difficulty when interpreting schedules that attempt to tap subjective, value-laden concepts. Therefore, informant-based measures need to be simplified, with the critical terms clearly defined and, where appropriate, accompanied by examples.

Accessing QOL for People with Intellectual Disability

Heal and Sigelman (1990) suggest that QOL can be assessed by an informant or reported directly by the subject. Also, such indicators can be authored by the

investigator or by subjects themselves. Ideally, people with disabilities who access services should be involved in the assessment of services in the most direct way possible. However, here there are some cautions. Overall, the research findings suggest people with ID overestimate their participation in activities (Crapps, Langone & Swaim, 1985). They also report higher levels of achievement than informants such as parents and staff suggest (Brown, Bayer & Brown, 1988). These authors have found that clients with ID are very accurate in rank ordering the necessities of life, but are poor at determining the resources required to meet their needs in any particular area. Furthermore, Burnett (1989) found that residents' satisfaction scores and those predicted for them by staff were weakly correlated, suggesting that staff were poor predictors of residents' satisfaction.

It is critical that researchers and practitioners develop methodologies to harness the perspectives of people with ID (Pitfield-Smith & Davey, 1990). Failure to do so "...is to continue to condone the exclusion of retarded people from taking an active participant roles in decisions affecting their own lives" (Hogg & Mittler, 1987, p. 283). Regardless of any moral considerations, such a failure is a breach of Australian law, in both Commonwealth and State jurisdictions (Commonwealth Disability Services Act, 1986; Tasmanian Disability Services Act, 1992). Collation and assessment of data to meet statutory obligations must be closely scrutinised according to a number of fundamental principles. These principles include the degree to which the process encourages people with ID to participate and supports them to make meaningful responses, the reliability of the results when subject to reassessment, the consistency of results when question formats are varied and the availability of collaborative or supportive data (Heal & Sigelman, 1990).

One of the major concerns when eliciting direct input from people with ID is that of acquiescence. Research has demonstrated that people with low IQ have a propensity to provide positive responses to questions put to them by interviewers and to provide answers they believe will be positively received by the interviewer (Sigelman, Budd, Spanhel & Schoenrock, 1981; Packer & Wright, 1983). For this reason, Burnett (1989) concludes that yes/no formats should be avoided when working with people who have moderate to severe intellectual disability. This author highlights the need for caution regarding the comprehension of items by people with ID, and their ability to discriminate between items such as happy and unhappy, like and dislike. Burnett also found that participants in his study were prone to mood changes and that their prevailing mood significantly influenced responses. The effect of these influences on data accuracy can be addressed by means of stringent interviewer training prior to data collection. In an effort to address response bias, Pitfield-Smith (1990) adopted an extended response format incorporating a number of categories, such as *yes*, *no*, *not sure*, *no response*. Cummins (1992) has attempted to make QOL assessments more accessible to people with ID by adopting a variety of visual scales in the form of ladders on which raters mark their responses. These scales can also be adapted using a series of facial pictograms, of the kind proposed in the QUOLIS (Quality Of Life Interview Schedule) piloted by Ouellette-Kuntz (1990). Of course, even with the development of more sophisticated augmentative communication techniques, difficulties gaining both objective and subjective data directly from people with limited receptive and expressive cognitive abilities remain. For this reason, proxy-based responses may provide an alternative data source.

Proxy Respondents and the Measurement of QOL

Assessing the QOL perspective of people with ID is fraught with difficulties.

Consequently, basing a service review or evaluation solely on the perspective of people with ID may be methodologically unsound. It presupposes that these people are able to fully comprehend, assess and provide accurate responses on all relevant issues, but research suggests this is not the case (McVilly, 1995). Proxy or surrogate respondents may offer a partial solution. To this end it is a common practice by service providers to seek opinions and advice from family members and support workers.

In the field of ID there is a dearth of literature concerning the use of proxy respondents. The majority of studies concerning proxy respondents are to be found in generic health service evaluation and epidemiological studies. Although these studies may appear far removed from the field of ID, examining such research may provide general information about proxy responses that may be usefully extrapolated to the use of proxies for people with ID. Furthermore, it may suggest some directions for research into proxy-based QOL evaluations in the field of ID.

Two critical issues raised by the use of proxy respondents concern the equivalence of information obtained by proxy and that obtained from individuals, and its comparative accuracy. Research findings provide a mixed picture. However, some common factors that impact on the effectiveness of proxy respondents do emerge. These factors include the nature of the issues under consideration and their degree of observability or objectivity, the degree to which specific information is required, the vantage point of the proxy (primarily their relationship to the subject), the proxy's

demographic characteristics, and the salience of the issue to the proxy (Mosely, Fredric & Wolinsky, 1986). In light of these findings, the existing evidence from the health-related literature will now be reviewed.

McCusker and Stoddard (1984) found no significant systematic differences between patient and caretaker mean ratings in a survey examining the impact of illness on elderly housebound patients. However, the level of agreement was lower when the patients were suffering from a terminal illness, when caretakers had a higher educational attainment than patients, and when the caretaker did not live in the same house. This survey exemplifies a situation where disparities between target and proxy responses do not necessarily indicate inaccuracies on the part of the proxy. The authors maintain that the subjects, who were mainly chronically ill and elderly, may not have accurately completed the survey due to their health status or their general level of awareness of the issues. For example, subjects generally reported having slept less than caretakers reported them to have slept. In this instance, the authors speculate that the subjects may not have been aware of their propensity for 'napping' during the day. The authors conclude that in some situations, proxies provide more accurate data than subjects themselves. This conclusion is consistent with the more recent findings of Nevitt et al. (1992). In a survey of the incidence of fractures in elderly patients, these authors found that proxy respondents were more accurate than patients themselves. The authors also found that proxies with a college education were more accurate, and subjects with a history of fractures and/or osteoporosis were inclined to overestimate the incidence of fractures.

The source of any differences between target and proxy responses is an important issue relating to the validity of proxy responses. On one hand low concurrence may

be attributed to poor ability on the part of the proxy in terms of their accuracy evaluating the issue under consideration, while the target gives an accurate evaluation. However, as the research by Nevitt et al. (1992) indicates, the reverse may be the case. Thus the issue of target/proxy concurrence needs to be viewed separately from the issue of accuracy in subjective data, including QOL. Nevertheless in the subjective measurement of QOL, the target's ratings or responses need to be considered as the "gold standard" because of the need to assess the individual's own perspective about the importance and adequacy of his or her present life circumstances.

The findings of Nevitt et al. (1992) raise two further issues to be considered when seeking proxy responses. First, response concurrence may be significantly affected by the complexity of the survey and the issues involved, relative to the educational attainment of respondents. For this reason, attention needs to be given to the layout of the survey material and the language employed. Technical terms should be avoided. Also, researchers assessing proxy accuracy relative to that of self-reports need to evaluate how conscious subjects are of the issues in question. Researchers should also consider the breadth of subjects' experience and their intellectual capacity to process that experience.

In an evaluation of health issues, Epstein et al. (1989) found that subject and proxy responses were highly and positively correlated when reporting overall health status, functional status, social activity and emotional health, and moderately correlated for life satisfaction. However, like McCusker and Stoddard (1984), they also observed a decrease in concordance between proxies and subjects as a function of subjects' disability. Epstein et al. suggest that the salience of the issue to the respondent is the

critical determinant of the response agreement. In other words, some issues are more readily observable than others and are therefore more easily reported by proxies.

Also, some issues are more significant to proxies and are therefore more readily recalled. For example, functional health is more readily observable than emotional or mental health. Similarly, negative emotions and feelings tend to be given greater expression than positive ones, and when forming impressions of others, observers tend to give more weight to negative expressions than to positive ones (Kanouse & Hanson, 1972).

Such findings are consistent with Magaziner, Hebel and Warren (1987) who conclude that a proxy's knowledge of a subject varies significantly by topic. For example, while proxies have been found to accurately report the incidence of specific diseases, their reports of subjective symptoms have not been consistent with those reported by subjects. Also, Hatch, Misra, Kabat, and Kartzmer (1991) observed that proxies who were spouses of subjects could accurately report the job titles and smoking habits of their partners, but they were poor predictors of their partner's alcohol consumption. Nevertheless, Graham and Jackson (1993) found that proxies were not likely to produce biased estimates of alcohol consumption.

Here it is evident that the interaction of a number of factors may account for various degrees of agreement and disparity between subject and proxy reports, including the residential relationship between the subject and the proxy and the nature of the topic in question. Halabi, Zurayk, Awaida, Darwish, and Saab (1992) report that proxy informants from the same household as subjects are good informants on health status pertaining to well-defined chronic conditions such as heart disease. However, lower levels of proxy-subject agreement were evident for conditions such as lower back

pain. The personal relationship between the proxy and the subject may also be a key factor. Tepper, Connally, Haltmeier, Smith, and Sweeney (1993) observed a high level of agreement between proxies' and subjects' reports of ulcers, cancer, diabetes and heart disease, with the strongest level of agreement in reports by spouses, followed by moderate agreement in reports by children, parents and siblings.

Studies that have failed to find satisfactory agreement between subjects and proxies have included reports of work-place herbicide exposure utilising wives as proxies (Boyle & Brann, 1992), and reports of reproductive histories (Fikree, Gray & Shah, 1993) and dietary reports (Hislop, Coldman, Zheng, Ng, and Labo 1992), both utilising husbands as proxies. It could be argued that these studies focused on well-defined and readily observable issues, but the question of issue salience provides a possible explanation for the discrepancies between subject and proxy reports. For example, spouses may not observe all types of food consumed by partners and may not be familiar with issues pertaining to their partner's work place. Furthermore, issues such as the birth weight of children and miscarriages may be culturally less significant to husbands than to wives, and therefore less accurately reported.

Emotional experience and personal preferences are the most difficult issues for obtaining proxy-subject concordance. Rende and Plomin (1991) examined the agreement between parents and their primary school aged children concerning life events that caused children to become upset. They found that parents significantly underestimated the impact of some events on their children, such as death of a close friend or a grandparent, a sibling leaving home and parental divorce. Further, they overestimated the impact of other events, such as arguments between parents and the loss of a job by a parent. Merkel (1984) reports disparity between physicians'

perceptions of their patients' satisfaction with health services and the reports of patients themselves. More seriously, Seckler, Meier, Mulvihill and Paris (1991) found that neither family members nor physicians could accurately predict the wishes of competent chronically ill patients concerning resuscitation. The authors found that most patients wanted to be resuscitated and that they believed both their family members and physicians could accurately represent their views. However, neither family members nor physicians were able to adequately predict the patients' wishes. The authors conclude that the results cast doubt on the usefulness of substituted judgement as an acceptable approach to medical decision-making for patients with diminished mental capacity. Similarly, in a survey of quality of life experienced by palliative care patients, Finlay and Dunlop (1994) reported that both relatives and professionals were poor predictors of patient views concerning physical, social, psychological and spiritual distress.

It is evident that as questions increase in detail and subjectivity, the degree of proxy-subject agreement decreases (Johnson et al., 1993) and that discrepancies in reporting arise as a function of multiple factors, including both the issue in question and the type of proxy involved (Lyon et al., 1992). The complexity of the issue, its observability and degree of salience to both the subject and the proxy are all key factors affecting the concurrence of proxy responses. In practical terms, the extent to which it is indeed possible for proxies to know about specific aspects of a person's life need to be taken into consideration when evaluating the correspondence between proxy and subjective accounts. Findings such as these in generic health-related studies suggest important considerations for the use of proxy respondents in the assessment of the QOL of people with intellectual disabilities, especially where the disability may indeed act as an important barrier to reliable evaluation.

Directions for Future Research

The quality of life experienced by people with disabilities is determined to a significant degree by the organisational policies and service delivery mechanisms that are established to support them. For this reason, process evaluation must remain a critical component in any QOL evaluation. To this end, the principles of Normalisation and Social Role Valorisation provide valuable guidelines for the design and implementation of services, together with standards against which such services may be monitored and reviewed.

Deinstitutionalisation and community integration continue to be the primary organisational policies and mechanisms by which positive changes are instigated in the lives of people with disabilities. These policies and mechanisms are equally applicable to people with ID who have never resided in an institution. For this reason, future studies will need to examine objective data concerning the success and failure of community placements, variations in people's daily activity patterns and social networks, together with their acquisition of adaptive behaviours and positive social adjustment.

Although objective evaluation formats are important when measuring QOL, the collation and quantification of subjective data seem paramount, especially when directly eliciting and evaluating consumer perspectives. Attempts have been made to design instrumentation for this purpose, but it is evident that further work is required to elicit data from people whose primary or sole means of communication is non-verbal. Also, when determining the issues to be assessed, researchers and service

providers need to consider evaluating their salience to individuals. To complement the individuals' perspective, subjective, outcome-based research will also need to encompass a variety of data sources, including input from third-party or proxy evaluators, who may be family members, friends, advocates or support staff.

Proxy-based evaluation has been the subject of extensive research in the area of generic health. However, there has been little research in populations of people with ID, whose defining characteristics often necessitate the involvement of proxies in the design and evaluation of their support services. There are currently available a number of instruments designed to assess the QOL construct, therefore it would seem appropriate to examine the utility of their use with proxy respondents, together with those characteristics of proxies that may enhance the accuracy of proxy-based reports.

References

- Aanes, D. & Moen, M. (1976). Adaptive behaviour changes of group home residents. *Mental Retardation*, 14, 36-40.
- Bachrach, L., & Lamb, H. (1982). Conceptual issues in the evaluation of the deinstitutionalisation movement. In G. Stahler & W. Tash (Eds.) *Innovative approaches to mental health evaluation*. New York: Academic Press.
- Banks-Mikkelsen, N. (1969). A metropolitan area in Denmark : Copenhagen. In R. Kugel and W. Wolfensberger (Eds.) *Changing patterns in residential services for the mentally retarded* (pp. 227-254). Washington : President's Committee On Mental Retardation, 1969.
- Barlow, J. (1992). *Quality of Life Questionnaire*. Adelaide, Australia: University of Adelaide.
- Barlow, J., & Kirby, N. (1991). Residential satisfaction of persons with an intellectual disability living in an institution or the community. *Australia and New Zealand Journal of Developmental Disabilities* 17, 7-23.
- Barton, R. (1959). *Institutional neurosis*. London: John Wright & Sons.
- Bellamy, G., Newton, J., LeBaron, M., & Horner, R. (1990). Quality of life and lifestyle outcomes: a challenge for residential programs. In R. Schallock and M. Begab (Eds.) *Quality of life: perspectives and issues*, (pp.127-138). Washington DC: American Association on Mental Retardation.
- Birenbaum, A., & Re, M. (1979). Resettling mentally retarded adults in the community - almost four years later. *American Journal of Mental Deficiency*, 83, 323-329.
- Bjaanes, A., & Butler, E. (1974). Environmental variation in community care facilities for mentally retarded persons. *American Journal of Mental Deficiency*, 78, 429-439.
- Bonanno, R., Gibbs, E., & Twardzicki, N. (1982). *Quality of Life Index*. Boston: Wrentham State School and Children's Hospital.
- Borthwick-Duffy, S. (1990). Quality of life for persons with severe or profound mental retardation. In R. Schallock and M. Begab (Eds.) *Quality of life: perspectives and issues* (pp. 177-190). Washington DC: American Association on Mental Retardation.
- Boyle, C., & Brann, E. (1992). Proxy respondents and the validity of occupational and other exposure data. *American Journal of Epidemiology*, 136, 712-721.
- Bradley, R., Caldwell, B., Brisby, J., Magee, M., & Whiteside, L. (1992). The HOME inventory: a new scale for families of pre and early adolescent children with disabilities. *Research into Developmental Disabilities*, 13, 313-333.

- Brown, R., & Bayer, M. (1991). *Rehabilitation Personal Questionnaire Manual: a guide to the individual's quality of life*. Calgary, Canada: University of Calgary.
- Brown, R., Bayer, M., & Brown, P. (1988). Quality of life: a challenge for rehabilitation agencies. *Australia and New Zealand Journal of Developmental Disabilities*, 14, 189-199.
- Brown, R., Bayer, M., & McFarlane, C. (1988). Quality of life among handicapped adults. In R. Brown (Ed.) *Quality of life for handicapped people* (pp. 111-146). London: Croom Helm.
- Bruininks, R., Hill, B., Weatherman, R. & Woodcock, R., (1986). *Inventory for Client and Agency Planning*. USA: Riverside Publishing Company.
- Bruininks, R., Woodcock, R., Weatherman, R., & Hill, B. (1985). *Scales of Independent Behaviour*. Chicago: DLM Teaching Resources.
- Burnett, P. (1989). Assessing satisfaction in people with an intellectual disability living in community-based residential facilities. *Australian Disability Review*, 1, 14-19.
- Butler, E., & Bjannes, A. (1978). Activities and the use of time by retarded persons in community care facilities. In G. Sackett (Ed.) *Observing behaviour Vol. 1* (pp. 379-402). London: University Park Press.
- Chun Yu, A., Jupp, J., & Taylor, A. (1996). The discriminant validity of the Lifestyle Satisfaction Scale (LSS) for the assessment of Australian adults with intellectual disabilities. *Journal of Developmental and Intellectual Disability*, 21, 3-15.
- Commonwealth of Australia (1986). *Disability Services Act, 1986*. Canberra, Australia: Commonwealth Government Printer.
- Conroy, J., & Feinstein, C. (1990). Measuring quality of life: where have we been, where are we going ? In R. Schallock and M. Begab (Eds.) *Quality of life: perspectives and issues* (pp. 227-234). Washington, DC: American Association on Mental Retardation.
- Craig, E., & McCarver, R. (1984). Community placement and adjustment of deinstitutionalised clients: issues and findings. *International Review of Research in Mental Retardation*, 12, 95-122.
- Crapps, J., Langone, J., & Swaim, S. (1985). Quantity and quality of participation in community environments by mentally retarded adults. *Education and Training of the Mentally Retarded*, June, 123-129.
- Cummins, R. (1993). *Comprehensive Quality of Life Scale (ComQol) Fourth Edition*. Toorak, Australia: School of Psychology, Deakin University.

- Daniel, T., & Vining, J. (1983). Methodological issues in the assessment of landscape quality. In I. Altman & J. Wohlwill (Eds.) *Behaviour and the natural environment*. New York: Plenum Press.
- Davey, V., & Pitfield-Smith, S. (1990). *A model for wholistic evaluation*. Adelaide, Australia: Barkuma Incorporated.
- Davey, V., & Pitfield-Smith, S. (1992). *Wholistic evaluation: an evaluation package developed by Barkuma Inc. for the review of residential programs*. Adelaide, Australia: Barkuma Incorporated.
- Diller, L., Fordyce, W., Jacobs, D., & Brown, M. (1982). *Rehabilitation indicators project*. New York: University Medical Centre.
- Donegan, C., & Potts, M. (1988). People with mental handicap living alone in the community - a pilot study of their quality of life. *British Journal of Subnormality*, 34, 10-22.
- Edgerton, R. (1984). The participant-observer approach to research in mental retardation. *American Journal of Mental Deficiency*, 88, 498-505.
- Edwards, J., & Klemmack, D. (1973). Correlates of life satisfaction: a re-examination. *Journal of Gerontology*, 28, 497-502.
- Emerson, E. (1985). Evaluating the impact of deinstitutionalisation on the lives of mentally retarded people. *American Journal of Mental Deficiency*, 90, 277-288.
- Epstein, A., Hall, J., Tognetti, J., Son, L., & Conant, L. (1989). Using proxies to evaluate quality of life. *Medical Care*, 27, 91-98.
- Estroff, S. (1981). Psychiatric deinstitutionalisation. *Journal of Social Issues*, 37, 116-131.
- Evans, G., Felce, D. & Hobbs, S. (1991). *Evaluating Service Quality*. Cardiff, UK: S.C.O.V.O.
- Eyeman, R., Demanie, G., & Lei, T. (1979). Relationship between community environments and resident changes in adaptive behaviour: a path model. *American Journal of Mental Deficiency*, 83, 330-338.
- Eyeman, R., O'Conner, G., Tarjan, G., & Justice, R. (1972). Factors determining residential placement of mentally retarded children. *American Journal of Mental Deficiency*, 76, 692-698.
- Eyles, J. (1990). Objectifying the subjective: the measurement of environmental quality. *Social Indicators Research*, 22, 139-153.
- Felton, B., & Shinn, M. (1981). Ideology and practice of deinstitutionalisation. *Journal of Social Issues*, 37, 158-172.

- Fikree, F., Gray, R., & Shah, F. (1993). Can men be trusted? A comparison of pregnancy histories reported by husbands and wives. *American Journal of Epidemiology*, 138, 237-242.
- Finlay, I., & Dunlop, R. (1994). Quality of life assessment in palliative care. *Annals of Oncology*, 5, 13-18.
- Flanagan, J. (1978). A research approach to improving our quality of life. *American Psychologist*, February, 138-147.
- Fotheringham, J. (1970). Retardation, family adequacy and institutionalisation. *Canada's Mental Health*, 18, 15-18.
- Fotheringham, J., Skeleton, M., & Haddinott, B. (1971). *The retarded child and his family: the effects of home and institution*. Toronto, Canada: Ontario Institute for Studies in Education.
- Gill, W. (1984). Monitoring the subjective well-being of chronically ill patients over time. *Community Health Studies*, 8, 288-296.
- Goffman, E. (1962). *Asylums*. Chicago: Aldine.
- Goode, D. (1988). *Quality of life: a review and synthesis of the literature*. New York: The Mental Retardation Institute.
- Graham, P. & Jackson, R. (1993). Primary vs proxy respondents : comparability of questionnaire data on alcohol consumption. *American Journal of Epidemiology*, 138, 443-452.
- Groeland, E. (1990). Structural elements of material well-being: an empirical test among people on social security. *Social Indicators Research*, 22, 367-384.
- Halabi, S., Zurayk, H., Awaida, R., Darwish, M., & Saab, B. (1992). Reliability and validity of self and proxy reporting of morbidity data. *International Journal of Epidemiology*, 21, 607-612.
- Hatch, M., Misra, D., Kabat, G., & Kartzmer, S. (1991). Proxy respondents in reproductive research : a comparison of self and partner reported data. *American Journal of Epidemiology*, 133, 826-831.
- Headey, B. (1981). The quality of life in Australia. *Social Indicators Research*, 9, 155-181.
- Heal, L., & Sigelman, C. (1990). Methodological issues in measuring quality of life of individuals with mental retardation. In R. Schallock and M. Begab (Eds.) *Quality of life: perspectives and issues* (pp.161-176) . Washington, DC: American Association on Mental Retardation.
- Heal, L. & Sigelman, C., & Switzky, H. (1978). Research on community residential alternatives for the mentally retarded. *International Review of Research on Mental Retardation*, 9, 210-243

- Hemming, H., Lavender, T., & Pill, R. (1981). Quality of life of mentally retarded adults transferred from large institutions to new small units. *American Journal of Mental Deficiency, 86*, 157-169.
- Hirst, M. (1989). Patterns of impairment and disability related to social handicap in young people with cerebral palsy and spina bifida. *Journal of Biosocial Science, 21*, 1-12.
- Hislop, T., Coldman, A., Zheng, Y., Ng, V., & Labo, T. (1992). Reliability of dietary information from surrogate respondents. *Nutrition and Cancer, 18*, 123-129.
- Hogg, J., & Mittler, P. (1987). *Staff training in mental handicap*. London: Croom Helm.
- Hudson, A., & Cummins, R. (1991). General service plans: an evaluation of their content within two service delivery systems. *Australia and New Zealand Journal of Developmental Disabilities, 17*, 401-411.
- Johnston, D. (1988). Towards a comprehensive quality of life index. *Social Indicators Research, 20*, 473-496.
- Johnson, R., Mandel, J.S., Gibson, R., Mandal, J.H., Bender, A., Gunderson, P., & Renier, C. (1993). Data on prior pesticide use collected from self and proxy respondents. *Epidemiology, 4*, 157-164.
- Kanouse, D., & Hanson, L. (1972). Negativity in evaluations. In Jones, E. et al. (Eds.) *Attribution: perceiving the causes of behaviour*. Morristown, NJ: General Learning Press.
- Klonoff, P., Snow, W., & Costa, L. (1986). Quality of life in patients 2 to 4 years after closed head injury. *Neurosurgery, 19*, 735-743.
- Lakin, K., Bruininks, R., & Sigford, B. (1981). Deinstitutionalisation and community adjustment - a summary of research issues. In R. Bruininks, C. Meyers, B. Sigford, & K. Lakin (Eds.) *Deinstitutionalisation and community adjustment of mentally retarded people*. Washington, DC: American Association on Mental Deficiency.
- Landesman, S. (1986). Quality of life and personal life satisfaction: definition and measurement issues. *Mental Retardation, 24*, 141-143.
- Lehman, A. (1983). The well-being of chronic mental patients: assessing their quality of life. *Archives of General Psychiatry, 40*, 369-373.
- Lewis, S., & Ryan, L. (1986). The quality of community and the quality of life. *Sociological Spectrum, 6*, 397-410.
- Lyon, J., Egger, M., Robinson, L., French, T., & Gao, R. (1992). Misclassification of exposure in a case control study: the effects of different types of exposure and

- different proxy respondents in a study of pancreatic cancer. *Epidemiology*, 3, 223-231.
- Magaziner, J., Hebel, J., & Warren, J. (1987). The use of proxy responses for aged patients in long-term care settings. *Comprehensive Gerontology*, 1, 118-121.
- McCarver, R., & Craig, E. (1974). Placement of the retarded in the community: prognosis and outcome. *International Review of Research in Mental Retardation*, 7, 146-199.
- McCusker, J., & Stoddard, A. (1984). Use of a surrogate for the Sickness Impact Profile. *Medical Care*, 22, 789-795.
- McVilly, K. (1995). Interviewing people with a learning disability about their residential service. *British Journal of Learning Disabilities*, 23, 138-142.
- Merkel, W. (1984). Physician perception of patient satisfaction: do doctors know which patients are satisfied? *Medical Care*, 22, 453-459.
- Mesibov, G. (1976). Alternatives to the principles of normalisation. *Mental Retardation* 14, 30-32.
- Milbrath, L. (1982). A conceptualization and research strategy for the study of ecological aspects of the quality of life. *Social Indicators Research*, 10, 133-157.
- Molony, H., & Taplin, J. (1988). Deinstitutionalisation of people with developmental disability. *Australia and New Zealand Journal of Developmental Disabilities*, 14, 109-122.
- Mosely, R., Fredric, D., & Wolinsky, F. (1986). The use of proxies in health surveys. Substantive and policy implications. *Medical Care*, 24, 496-510.
- Nevitt, M., Cummins, S., Browner, W., Seeley, D., Cauley, J., Vogt, T., & Black, D. (1992). The accuracy of self-report of fractures in elderly women: evidence from a prospective study. *American Journal of Epidemiology*, 135, 490-499.
- Nirje, B. (1970). The normalisation principle. *British Journal of Subnormality* 16, 62-70.
- Nirje, B. (1985). The bases and logic of the normalisation principle. *Australia and New Zealand Journal of Developmental Disabilities*, 11, 65-68.
- Novak, A., & Heal, L. (1980). *Integration of developmentally disabled individuals into the community*. Baltimore: Paul H. Brookes.
- O'Brien, J. (1984). *The principle of normalisation: a foundation for effective services*. Atlanta, GA: Georgia Advocacy Office.
- O'Conner, G. (1976). *Home is a good place: a national perspective of community residential facilities for developmentally disabled persons*. Washington, DC: American Association on Mental Retardation.

- Ouellette-Kuntz, H. (1990). A pilot study in the use of the quality of life interview schedule. *Social Indicators Research*, 23, 283-298.
- Packer, J., & Wright, J. (1983). *I like where I live: an evaluation of group home style living*. Woden, Australia: Department of Social Security.
- Parmenter, T. (1988). *The development of a quality of life model as an outcome measure of rehabilitation programs for people with developmental disabilities*. Paper presented at the 9th Conference of Young Adult Institute, Employment, Integration and Community Competence, New York.
- Parmenter, T. (1992). Quality of life of people with developmental disabilities. *International Review of Research in Mental Retardation*, 18, 247-287.
- Pickle, L., Brown, L., & Blot, W. (1983). Information available from surrogate respondents in case-control interview studies. *American Journal of Epidemiology*, 118, 99-108.
- Pitfield-Smith, S., & Davey, R. (1990). *Consumer participation: an essential component of disability program evaluation*. Paper presented at National Evaluation Conference, July 1990, Sydney, Australia.
- Rende, R., & Plomin, R. (1991). Child and parent perceptions of the upsettingness of major life events. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 32, 627-633.
- Riddle, J. & Riddle, H. (1982). *The Joy Quotient: observations on our need to prioritise pleasure in the lives of the severely handicapped*. Occasional Paper. USA: National Association of Superintendents of Public Institutions for the Mentally Retarded.
- Ridley, S., & Wallace, P. (1990). Quality of life after intensive care. *Anaesthesia*, 45, 808-813.
- Rotegard, L., Bruininks, R., Holman, J., & Lakin, C. (1985). Environmental aspects of deinstitutionalisation. In R. Bruininks & K. Lakin (Eds.) *Living and learning in the least restrictive environment* (pp. 115-145). Baltimore: Paul Brooks Publishing Co.
- Rowitz, L. (1989). Editorial: Trends in mental retardation in the 1990s. *Mental Retardation*, 27, iii-vi.
- Sandler, A., & Thurman, S. (1981). Status of community placement research: effects on retarded citizens. *Education and Training of the Mentally Retarded*, 16, 245-251.
- Schallock, R. (1989). *Services for developmentally disabled adults: development, implementation and evaluation*. Baltimore: University Park Press.

- Schallock, R. & Begab, M. (1990). *Quality of life: perspectives and issues*. Washington DC, USA: American Association on Mental Retardation.
- Scheerenbeger, R. (1974). A model for deinstitutionalisation. *Mental Retardation*, 12, 3-7.
- Seckler, A., Meier, D., Mulvihill, M., & Paris, B. (1991). Substituted judgement: how accurate are proxy predictions. *Annals of International Medicine*, 115, 92-98.
- Segal, M., & Schall, R. (1994). Determining functional health status and its relation to disability in stroke survivors. *Stroke*, 25, 2391-2397.
- Shye, S. (1989). The systematic life quality model: a basis for urban renewal evaluation. *Social Indicators Research*, 21, 343-378.
- Sigelman, C., Budd, E., Spanhel, C., & Schoenrock, C. (1981). When in doubt, say yes: acquiescence in interviews with mentally retarded persons. *Mental Retardation*, 2, 53-58.
- Sparrow, S., Balla, D. & Cicchetti, D. (1984). *Vineland Adaptive Behaviour Scale*. Circle Pines, Minnesota : American Guidance Service.
- Spreitzer, E., & Snyder, E.E. (1974). Correlates of life satisfaction among the aged. *Journal of Gerontology*, 29, 28-39.
- Standon, A., & Schwartz, W. (1954). *The mental hospital*. London: Tavistock.
- Sullivan, C., Vitello, S., & Foster, W. (1988). Adaptive behaviour of adults with mental retardation in a group home: an intensive case study. *Education and Training in Mental Retardation*, March, 76-81.
- Szaz, T. (1973). *The manufacture of madness*. Frogmore, England: Paladin.
- Taylor, S., & Bogdan, R. (1990). Quality of life and the individual's perspective. In R. Schallock and M. Begab (Eds.) *Quality of life: perspectives and issues* (pp. 27-40). Washington, DC: American Association on Mental Retardation.
- Tepper, A., Connally, L., Haltmeier, P., Smith, E., & Sweeney, M. (1993). Knowledge of medical history information among proxy respondents for diseased study subjects. *Journal of Clinical Epidemiology*, 46, 1243-1248.
- Thompson, T., & Carey, A. (1980). Structured normalization: intellectual and adaptive changes in a residential setting. *Mental Retardation*, 18, 193-197.
- Thorndike, E. (1939). *Your city*. New York: Raven Press.
- Tuckey, B., & Tuckey, L. (1981). *An ordinary place: The Stone House - a community work approach to disabled people*. Windsor, England: NFER - Nelson Publishing Co.

- Vitello, S., & Soskin, R. (1985). *Mental retardation: its social and legal context*. Englewood Cliffs, NJ: Prentice-Hall.
- Windle, C., Stewart, E., & Brown, S. (1961). Reasons for community failure of released patients. *American Journal of Mental Deficiency*, 66, 213-217.
- Wing, J. (1962). Institutionalism in mental hospitals. *British Journal of Social and Clinical Psychology*, 1, 38-51.
- Wing, L. (1989). *Hospital closure and the resettlement of residents*. Aldershot, UK: Gower Publishing Co.
- Wolfensberger, W. (1972). *The principles of normalization*. Ontario, Canada: National Institute on Mental Retardation.
- Wolfensberger, W. (1983). Social role valorization: a proposed new term for normalisation. *Mental Retardation*, 21, 234-239.
- Wolfensberger, W., & Thomas, S. (1983). *PASSING Manual*. Ontario, Canada: National Institute on Mental Retardation.
- Zigler, E., & Balla, D. (1977). Impact of institutional experience on the behaviour & development of retarded persons. *American Journal of Mental Deficiency*, 82, 1-11.

This chapter appears to be the equivalent of a submitted manuscript published by Taylor and Francis as: Keith R McVilly, Rosanne M Burton-Smith & John A Davidson (2000) Concurrence between subject and proxy ratings of quality of life for people with and without intellectual disabilities, Journal of Intellectual & Developmental Disability, 25:1, 19-39, DOI: 10.1080/132697800112767

The online version of the article is available from Taylor and Francis Online at: <https://www.tandfonline.com/doi/abs/10.1080/132697800112767>

**Concurrence Between Subject and Proxy Ratings of QOL
for People With and Without Intellectual Disability :
the Role of Mediating Factors**

Keith R. McVilly B.A., Grad. Dip. Psy., MAPS

A journal article submitted as partial requirement for the degree
Master of Psychology (Clinical)
in the Department of Psychology, University of Tasmania at Hobart,
September, 1997.

Abstract

Two studies were conducted; the first utilising ComQol-A4 (Cummins, 1993), examined concurrence between non-disabled subjects' self-reported quality of life (QOL) and ratings made on their behalf by proxies who were either a parent or a sibling ($N = 78$ subject/proxy pairs). The second study, utilised ComQol-ID4 (Cummins, 1993), and examined concurrence between QOL ratings made by subjects with mild intellectual disability and proxies who were either parents or support workers, acting in the role of *loco parentis* ($N = 24$ subject/proxy pairs). In both studies the effects on concurrence of proxy empathy and a number of demographic variables were examined. Results from both studies indicated a comparatively high degree of subject/proxy concurrence, regardless of the characteristics of either proxies or subjects. Over or underestimation of ratings by proxies was minimal. These results support the use of proxy-based reports utilising ComQol. However, given that subjects and proxies both tended to report QOL at the upper end of the rating scale it was proposed the comparatively high degree of concurrence may have arisen as a result of a possible positive response bias on the ComQol. Though there were a number of significant interactions, there were no significant main effects for any of the independent variables. Subsequently there was insufficient evidence that empathy or any of the demographic variables investigated directly affected subject/proxy concurrence. However, methodological issues relating to the way in which concurrence was calculated and/or the possible positive response bias on the ComQol may have masked these effects.

Shallock (1989) and Rowitz (1989) predicted quality of life (QOL) would emerge as one of the most important areas of research in the field of intellectual disability (ID), replacing deinstitutionalisation, normalisation and community adjustment as the pre-eminent issue of the 1990s. In fact legislation such as the Commonwealth Disability Services Act (1986), and contemporary management practices now require that data pertaining to the quality of life experienced by service users be available to guide the development of services for people with disabilities (Davey & Pitfield-Smith, 1990 & 1992; Evans, Felce & Hobbs, 1991). Furthermore, both Parmenter (1992) and Emerson and Hatton (1996) assert that the evaluation of QOL is fundamental to the evaluation of services for people with ID.

Despite the recognition of its importance and an ever-expanding literature, the composition of QOL remains controversial (Fogarty & Cummins, 1994). Generally, the only point of agreement among theorists and researchers is that QOL is a multi-dimensional construct comprising both objective and subjective factors (Barlow & Kirby, 1991; Brown & Bayer, 1991; Borthwick-Duffy, 1992; Cummins, 1993).

Objective factors include type of accommodation, use of medication and the extent of an individual's social network. Subjective factors are generally measured in terms of personal satisfaction with aspects of life. Felce and Perry (1993) and Emerson and Hatton (1996) suggest that any evaluation of QOL is dependent upon the assessment of both organisational processes and personal outcomes, together with an indication of the relative importance that individuals place on specific aspects of life, and their reported satisfaction with those aspects of life. Furthermore, Chun Yu, Jupp and Taylor (1996) propose that QOL is best understood as a dynamic construct. For

example, personal priorities and satisfaction with life vary as a result of changes to both objective and subjective factors, and people's personal frames of reference vary in response to a combination of their current experience and the salience of previous experience.

The question of concurrence between self-reported ratings of QOL and those made by proxies is one of considerable importance in both the provision and the evaluation of services for people with ID. Due to their disability, clients may be limited in their capacity to effectively evaluate the services they use, and more importantly to provide information regarding their attitude to service alternatives and personal preferences for inclusion in their individual service delivery plans (McVilly, 1995). In these situations, QOL reports made by service workers and family members on behalf of clients with ID often form the basis of both individual client plans and organisational development strategies. Nevertheless, there is very little information on the validity of proxy information when accessing the QOL of people with ID, and how informant bias and other factors may affect its accuracy.

A few studies have addressed the validity of proxy-based QOL data in the field of ID by examining the degree of concurrence between subjects and proxies. Burnett (1989) reports low correlation between the satisfaction ratings of residents with ID and those predicted for them by staff, suggesting staff were poor predictors of residents' self-reported life satisfaction. Similarly, Rigby, McCarron and Ribby (1990), utilising the Ward Atmosphere Scale found that staff responses differed significantly from those of patients with disabilities on half of the questions. Similarly, Epstein, Hall,

Tognetti, Son and Conant (1989) found that staff rated their clients as more severely impaired than did the clients themselves. Surprisingly, staff-client agreement was not necessarily fostered by increased time together. Epstein et al. speculate that staff consistently overestimated the severity of their clients' health status, relative to the clients' own reports, in an effort to justify the time staff spent providing support. These limited research findings indicate a need for caution when interpreting proxy-based data. Concurrence is generally low and the nature of the subject/proxy relationship (i.e., client/staff), together with the degree of the client's disability may represent intervening variables affecting the concurrence of subject and proxy reports.

It is evident that there is a dearth of research concerning proxy-based QOL reports for people with ID. Furthermore, most studies have only examined subject/proxy concurrence with clients who have ID in relation to evaluations made by staff proxies. However, family members may also be a valuable source of proxy data, but research in this area is notable by its scarcity. It is therefore necessary to examine research in related areas for findings that may have a bearing on the use of family members as proxies for people with ID. Research concerning these issues can be found mainly in the health-related QOL literature. For example, in a survey that investigated social factors contributing to a sense of well-being, Andrews and Withey (1976) reported that ratings made by family members did not significantly correlate with those of clients themselves. In a study examining parents' predictions of their child's rating of a traumatic event, Rende and Plomin (1991) found low levels of parent-child agreement. Similarly, Fikree, Gray and Shah (1993) report low levels of agreement between husbands and wives concerning pregnancy histories. In contrast, while

Epstein et al. (1989) discovered that subjects' responses and proxy responses by family members' were strongly and significantly correlated in the case of overall health, functional status, social activity and emotional health, and they were moderately correlated in the case of life satisfaction measures. Fontana, Marcus, Dowds and Hughes (1980) found significant correlation between the reports of hospital patients and significant others concerning negative affect, but failed to find any significant relationship in accounts of positive affect. However, based on the social attribution literature, caution is required when interpreting such data. It has been found that observers tend to give greater weight to negative rather than positive affect, and emotional expression is usually only selectively revealed by subjects (Kanouse & Hanson, 1972).

It is apparent that studies concerning concurrence among family members reveal mixed findings, possibly due to the variability of the issues explored and the instruments used. Nevertheless, the literature reports overall low levels of concurrence between subject and proxy-based QOL reports, and suggests that even observers with close familial relationships are limited in their capacity to gain insight into and accurately report on the psycho-emotional state of significant others. Factors other than long-standing and intimate personal relationships may therefore mediate concurrence.

Researchers have investigated factors that may influence the level of agreement between proxies and subjects mainly in relation to health issues. Nevitt et al. (1992) found that proxies with higher educational levels exhibited greater concurrence with

their elderly parents' reports of their fracture histories. However, McCusker and Stoddard (1984) investigated subject/proxy concurrence for patients with a terminal condition, and found less concurrence in ratings of the impact of illness where proxies had a higher educational attainment. Halabi, Zurayk, Awaida, Darwish, and Saab (1992) found that proxy informants in the same household as subjects showed greater concurrence with other household members in reporting health status, compared with proxy informants who lived separately from their subjects. In contrast, McCusker and Stoddard found that when caretakers lived in the same house as patients, rating similarity was lowest. These studies have produced contradictory findings that require further investigation.

From the present review it is apparent that there are few studies investigating subject/proxy concurrence focusing on people with ID. From the few studies that are available and from the health literature, it appears that concurrence is generally low, a factor that may have bearing on the use of proxy data when developing service plans for people with ID. Nevertheless, proxy data remain important in this field because people with ID are often limited in their capacity to provide direct data pertaining to their QOL. It is also apparent from the health-related studies that factors such as the type of information elicited the degree of contact between subject and proxy and the nature of the subject/proxy relationship may mediate concurrence. These and other factors are worthy of further investigation in relation to subject/proxy concurrence in general, and specifically for people with ID. Furthermore, it is possible that ID may constitute an additional barrier to subject/proxy concurrence. Research investigating concurrence in QOL evaluations by people with and without ID is therefore needed to

clarify these issues, and to identify factors that may mediate concurrence in both populations. To achieve these aims two studies were undertaken, one in which subjects and proxies were both drawn from a non-disabled population, and the other, with non-disabled proxies and subjects with ID.

Study 1 : Factors Mediating Subject/Proxy Concurrence in QOL Ratings among Non-disabled Family Members.

Aim and Hypotheses

This study was conducted to investigate the degree of concurrence on QOL ratings between non-disabled subjects and proxies using the ComQol-A4 (Cummins, 1993). The effects of a range of demographic variables and one psychological variable on proxy-subject concurrence were explored. In view of the paucity of research in this area the present study was exploratory, and investigated several non-directional hypotheses. Given the possible effect of observability suggested in previous studies, it was hypothesised that cohabitation between proxies and subjects would affect concurrence. It was also predicted that gender might be a salient factor influencing concurrence. This factor was investigated by examining the effect of proxy gender on concurrence, and the effect of gender similarity and difference between proxies and subjects. In view of possible generational effects it was hypothesised that concurrence may depend on whether proxies and subjects were in a parent-child relationship, or a sibling relationship. It was also predicted that concurrence might be affected by the degree of proxy empathy. Simple effects as well as complex interactions between these factors were explored in the present study.

Method

Participants

Participants in Study 1 ($N = 78$ subject/proxy pairs) included Tasmanian university students and public servants, as well as members of their immediate families (i.e., first-degree relatives). University students were sampled from first and second year psychology classes. Students who agreed to participate in turn recruited family members. In all, they constituted 55 subject/proxy pairs. Public servants from the Department of Community Services and the State Fire Service were included to give a broader sample base for the study. They were recruited from their place of work and also recruited family members. In total there were 12 subject/proxy pairs from Community Services and 11 subject/proxy pairs from the State Fire Service.

There were 33 male and 45 female subjects in the whole sample, ranging in age from 18 to 48 years ($M = 21$ years 11 months, $SD = 8$ years 3 months). Proxies were all members of the subjects' families. They ranged in age from 18 to 82 years ($M = 35$ years 11 months, $SD = 17$ years 1 month). There were 42 same-sex pairs and 36 opposite-sex pairs that included 21 mothers, 18 fathers, 24 sisters and 15 brothers of subjects. The length of association between proxies and subjects ranged from 15 to 48 years ($M = 21$ years 3 months, $SD = 8$ years 4 months), with 51 proxies reporting that they lived with their relative and 27 reporting that they lived separately. A total of 57 proxies reported being in daily contact with their relative and 21 reported contact between three times per week and once a month.

Instrumentation

QOL was measured using the Comprehensive Quality of Life Scale For Adults, Fourth Edition or ComQol-A4 (Cummins, 1993 - see Appendix 1). It is a self-report questionnaire, incorporating both objective and subjective dimensions of QOL. On each dimension, QOL items are divided into seven life domains, comprising material well-being, health, productivity, intimacy, safety, participation in the community and emotional well-being. The Objective QOL is calculated by summing respondents' ratings on 21 QOL items (three items for each of the seven life domains) pertaining to issues such as accommodation, medication and recreational activities. The Subjective QOL is generated by multiplying respondents' ratings of importance on items from each of the seven life domains by their corresponding ratings of satisfaction for items in each domain ($I \times S$). Higher scores indicate higher quality of life. The validity and reliability of ComQol-A4 is reported as acceptable (Cummins, McCabe, Romeo & Gullone, 1994).

Empathy was measured by the Mehrabian and Epstein Empathy Questionnaire (MEEQ) (Mehrabian & Epstein, 1972 - see Appendix 3). The MEEQ is a 33-item self-report questionnaire designed to measure emotional empathy i.e., the capacity of a respondent to recognise another's feelings and to share those feelings. Respondents indicate their degree of agreement or disagreement with items on a nine-point scale (+4 to -4). Statements indicating non-empathetic traits are re-coded and an algebraic sum of all responses obtained. Higher scores indicate greater empathy.

Procedure

Potential participants were given a standard introduction to the investigation and volunteers were then provided with a package consisting of colour-coded questionnaires for themselves and a family member who was to act as a proxy. Written instructions and prepaid envelopes for return of questionnaires were also provided. Subjects completed their own ComQols and recruited a family member who completed a ComQol in proxy mode i.e., as they believed their family member (the subject) would rate the items. Proxies and subjects were instructed to complete the ComQols without conferring. Proxies also completed the MEEQ. In some cases, reciprocal ComQol ratings were used; i.e, some sibling pairs completed one set of ComQols and then reversed subject/proxy roles to complete another set of ComQols. Questionnaires were returned anonymously by mail and return of the ComQols indicated consent to participate. ComQol and MEEQ protocols were hand-scored according to instructions contained in the respective manuals.

Results

The Dependant Variable

Concurrence between subject and proxy ratings for both Objective and Subjective QOL was investigated as a dependent variable, expressed as the degree of discrepancy between subject and proxy ratings on the ComQol. Concurrence was calculated separately for the Objective and Subjective ComQol domains. In each domain, the discrepancy between subject and proxy ratings was first calculated individually for the seven sub-scales, with sub-scale discrepancy scores expressed as the absolute value of subject ratings minus proxy ratings. This value was then

subtracted from the maximum possible discrepancy score for each sub-scale in order to obtain a sub-scale concurrence score. Finally, the seven sub-scale concurrence scores were added to give a total score indicating subject/proxy concurrence.

Objective Concurrence Scores

For the Objective domain, each of the seven sub-scales consisted of three questions that were rated from 1 to 5, therefore the minimum score on any Objective sub-scale was 3 and the maximum was 15. If a subject rated all three questions as 1 and a proxy rated all three questions as 5 (i.e., maximum discrepancy) then a maximum possible discrepancy score of 12 would be gained (i.e., $|3-15| = 12$). Actual subject/proxy discrepancy scores were subtracted from this theoretical maximum to achieve a measure of concurrence. For example, 12 (maximum sub-scale discrepancy) - 7 (actual subject/proxy discrepancy) = 5 (concurrence score). Using this formula, the minimum possible concurrence score on any Objective sub-scale was 0 (i.e., $12 - |3-15| = 0$). Thus, the possible range of Objective concurrence scores was 0 to 84 (i.e., 7 sub-scales x a minimum discrepancy of 0 and a maximum discrepancy of 12).

Subjective Concurrence Scores

For the measure of Subjective QOL on the ComQol, it was first necessary to determine respondents' ratings of Importance and Satisfaction on each of the 7 sub-scales. Subjective QOL is then calculated by multiplying ratings of Importance by ratings of Satisfaction ($I \times S$). The range of possible ratings for Importance is 1 to 7 and the range of possible ratings for Satisfaction is 1 to 5. Therefore the possible

range of Subjective QOL is from 1 (i.e., Importance rating of 1 x Satisfaction rating of 1) to 35 (i.e., Importance rating of 7 x Satisfaction rating of 5).

Concurrence was calculated by applying a similar formula to that used for the Objective QOL. For example, if a subject's Subjective rating was 1 and a proxy's rating was 35 (i.e., maximum possible discrepancy) then the minimum possible discrepancy score would be 34 (i.e., $|1-35| = 34$). Actual subject/proxy discrepancy scores were subtracted from this theoretical maximum to achieve a measure of concurrence. For example, 34 (maximum sub-scale discrepancy) - 27 (actual subject/proxy discrepancy) = 7 (concurrence score). With this formula, the minimum possible Subjective concurrence score was therefore 0 (i.e., $34 - |1-35| = 0$), while the maximum was 34. Therefore the possible range of subjective concurrence scores was 0 to 238 (i.e., 7 sub-scales x a minimum discrepancy of 0 and a maximum of 34).

The Independent Variables

Variables relating to the hypotheses were expressed as dichotomous between-subjects factors. These variables were Proxy Living Arrangements (co-habitation with subject or living separately), Proxy Relationship (parent or sibling), Proxy Gender (male or female), Subject/Proxy Gender Similarity (same or different) and Proxy Empathy (high or low empathy). High and low empathy groups were established by a median split in the ranked MEEQ ratings of all proxies. The high empathy group had scores equal to or greater than 47 and the low empathy group had scores less than 47.

Means and standard deviations for MEEQ scores for the present sample and for a standardised sample can be found in Appendix 3.

To test specific hypotheses, mean concurrence scores and standard deviations were calculated according to each of the between-groups factors. Hypotheses relating to the effects of empathy and the demographic variables were tested separately for Objective and Subjective concurrence scores. For this purpose, a series of 2 (Living Arrangements) x 2 (Relationship) x 2 (Subject /Proxy Gender Similarity) x 2 (Proxy Gender) x 2 (Empathy) ANOVAs were conducted using SPSS. However, analyses were complicated by the combination of a number of empty cells and unequal cell frequencies. It was therefore not possible to determine the higher order interactions and the analyses were re-run with all but the main effects and two-way interactions suppressed. An alpha level of .05 was used for all analyses.

Analysis of Factors Influencing Concurrence for Objective QOL

For Objective QOL, analyses revealed no significant main effects or interactions ($p > .05$). *F* values relating to these analyses appear in Appendix 4. Indeed, Table 1 reveals minimally different concurrence scores that are close to the maximum possible concurrence of 84. The standard deviations indicate little variability in the scores, which are closely clustered around the mean.

Table 1.
Mean concurrence scores for Objective QOL ratings by 78 subject/proxy pairs.

Independent Variables		<i>n</i>	<i>M</i>	<i>SD</i>
Living Arrangements	- with subject	51	72.57	4.51
	- separately	27	72.48	3.38
Proxy Relationship	- parent	39	72.46	4.41
	- sibling	39	72.62	3.90
Proxy Gender	- male	33	72.15	4.11
	- female	45	72.82	4.17
Proxy/Subject Gender	- same	42	72.57	3.68
	- opposite	36	72.50	4.66
Proxy Empathy	- low	39	72.28	4.06
	- high	39	72.79	4.24

Note : Possible range of concurrence = 0 to 84

Analysis of Factors Influencing Concurrence for Subjective QOL

For Subjective QOL, analyses revealed no significant main effects ($p > .05$). For F values relating to these analyses please refer to Appendix 4. Table 2 shows mean concurrence scores for Subjective QOL that are only minimally different and that approach the maximum possible concurrence of 238. Furthermore, standard deviations indicate little variability in scores.

Table 2.

Mean concurrence scores for Subjective QOL ratings by 78 subject/proxy pairs.

Independent Variables		<i>n</i>	<i>M</i>	<i>SD</i>
Living Arrangements	- with subject	51	204.28	14.99
	- separately	27	201.00	16.68
Proxy Relationship	- parent	39	203.10	17.26
	- sibling	39	203.18	13.90
Proxy Gender	- male	33	203.96	14.29
	- female	45	202.53	16.58
Proxy/Subject Gender	- same	42	203.17	13.35
	- opposite	36	203.11	18.01
Proxy Empathy	- low	39	202.46	15.75
	- high	39	203.83	15.56

Note : Possible range of concurrence = 0 to 238

The analysis indicate that none of the five factors directly influenced concurrence to a significant degree. However, of all the possible two-way interactions, three were significant, including Proxy Empathy x Proxy Living Arrangements, $F(1,53) = 4.66$, $p < .05$, Proxy Empathy x Proxy Gender, $F(1,53) = 5.74$, $p < .05$ and Proxy Relationship to Subject x Proxy Gender in Relation to Subject Gender, $F(1,53) = 5.21$, $p < .05$. For F values relating to all two-way interactions, see Appendix 4. Nevertheless, in the absence of any significant main effects, a cautious interpretation of these interactions is warranted.

Table 3 shows the mean concurrence scores and standard deviations relating to the interaction between Proxy Empathy and Proxy Living Arrangements. Unrelated

samples *t*-tests were used to investigate the simple effects, and indicated that the only significant difference was in the high empathy group. Here the mean concurrence scores for proxies living with subjects was significantly higher than those for proxies living separately from subjects, $t(49) = 2.59, p = .01$ (see Table 3 for means and standard deviations).

Table 3.

Mean concurrence scores for Subjective QOL ratings by 78 subject/proxy pairs.

Proxy Empathy	Proxy Living Arrangements	
	With Subject	Separately from Subject
Low	200.39 (17.41) $n = 26$	206.62 (11.24) $n = 13$
High	208.32 (10.92) $n = 25$	195.79 (19.46) $n = 14$

Note: Standard deviations appear in parentheses.

Table 4 displays the mean concurrence scores and standard deviations relating to the interaction of Proxy Empathy and Proxy Gender. Unrelated samples *t*-tests were used to specify the simple effects contributing to this interaction. Only one significant difference was found. For the low empathy condition there was a gender difference, with male proxies exhibiting significantly higher mean concurrence with their subjects than female proxies, $t(37) = 2.18, p = .04$ (see Table 4 for means and standard deviations).

Table 4.
Mean concurrence scores for Subjective QOL ratings by 78 subject/proxy pairs.

Proxy Empathy	Proxy Gender	
	Male	Female
Low	205.96 (11.20) <i>n</i> = 27	194.58 (21.53) <i>n</i> = 12
High	195.00 (23.15) <i>n</i> = 6	205.42 (13.65) <i>n</i> = 33

Note: Standard deviations appear in parentheses.

Table 5 shows mean concurrence scores and standard deviations relating to the interaction of Proxy Gender in Relationship to Subject Gender, and Proxy Relationship to Subject. Despite evidence of a significant interaction, unrelated samples *t*-tests for simple effects revealed no significant differences in mean concurrence scores ($p > .05$), possibly due to a cross-over effect evident in the mean concurrence scores (see Table 5 for means and standard deviations).

Table 5.
Mean concurrence scores for Subjective QOL ratings by 78 subject/proxy pairs.

Proxy Gender in Relationship to Subject Gender	Proxy Relationship to Subject	
	Parent	Sibling
Same	200.68 (16.57) n = 22	205.90 (8.14) n = 20
Opposite	206.24 (18.13) n = 17	200.32 (17.92) n = 19

Note: Standard deviations appear in parentheses.

Over or Underestimation of Subject QOL Ratings by Proxies

Given the comparatively high degree of subject/proxy concurrence and the possible practical applications for proxy-based QOL data, the significance of the differences between subject and proxy QOL ratings on ComQol-A4, and the direction of these differences were investigated. To this end, unrelated samples *t*-tests were conducted on mean subject and proxy ratings of Objective and Subjective QOL to investigate whether proxies significantly overestimated or underestimated the ratings made by their subjects. For Objective QOL proxies ($M = 10.75$, $SD = 1.04$) significantly underestimated subject ratings ($M = 11.02$, $SD = 1.20$); $t(77) = 2.20$, $p = .03$. However for Subjective QOL, proxies' mean ratings of importance ($M = 5.44$, $SD = 0.63$) did not significantly differ from subjects' mean ratings ($M = 5.27$, $SD = 0.78$); $t(77) = 1.96$, $p = .06$. Similarly, proxies' mean ratings of satisfaction ($M = 3.87$, $SD = 0.42$) did not significantly differ from subjects' mean ratings ($M = 3.93$, $SD = 0.57$);

$t(77) = 0.78, p = .44$. Furthermore, examination of the raw data revealed that for both subjects and proxies the mean ratings consistently approached the scale maximum for Objective QOL (i.e., 15) and for Subjective QOL on ratings of both importance (i.e., 7) and satisfaction (i.e., 5).

Discussion

Study 1 investigated the possible effects of one psychological and four demographic variables on subject/proxy concurrence concerning ratings of QOL utilising the ComQol-A4. For the Objective domain, there were no significant effects and therefore insufficient evidence to support the contention that factors such as subject/proxy living arrangements, relationships, gender and proxy empathy would influence the degree of concurrence on their ratings of QOL. In all cases, the mean scores showed a high degree of subject/proxy concurrence on ratings of Objective QOL, regardless of the characteristics of the proxies. While analysis of the raw scores suggested that proxy ratings of Objective QOL significantly underestimated subject ratings, the meaningfulness of this difference in real terms could be questioned. In other words, the difference in scores of less than 1 point on a scale of 1 to 15 would not be expected to impact greatly on the use of proxy-based data in actual assessment situations. Overall, the present results indicate that parental and sibling proxies are effective predictors of Objective ComQol ratings provided by a member of their family.

For the Subjective domain, there were no significant main effects. The significant interactions that emerged should therefore be interpreted cautiously. While it was

found that Proxy Empathy interacted with Proxy Living Arrangements to influence concurrence, significant differences were only evident for the high empathy group. As might have been predicted, subject/proxy concurrence was significantly higher when subjects and proxies co-habitated than when they lived separately.

Proxy Gender and Proxy Empathy also interacted to influence concurrence.

However, analysis of the simple effects indicated that only in the low empathy group did gender make a difference to the degree of subject/proxy concurrence. Here, male proxies achieved greater concurrence with their respective subjects than did female proxies. In the high empathy group the analysis indicated that gender was not a significant factor. Furthermore, there were no significant effects of empathy on concurrence scores in either male or female proxy groups.

Similarity, subject/proxy Gender Similarity interacted with subject/proxy Relationships to affect the degree of concurrence. However, simple effects tests failed to detect any significant differences, possibly due to a crossover effect in the data. That is, mean concurrence scores were very similar for parent/child pairs of the same gender and sibling pairs of the opposite gender. Furthermore, opposite gender parent/child pairs and same gender sibling pairs also exhibited highly similar mean concurrence scores.

Despite the presence of some significant interactions, there appears to be insufficient evidence to strongly support the hypothesis that any of the factors investigated would influence concurrence. Overall, the results indicated a relatively high degree of

concurrence between subject and proxy ratings on ComQol-A4 for measures of both Objective and Subjective QOL. This high degree of concurrence generally supports the use of proxy-based QOL assessments utilising ComQol-A4, where proxies are either parents or siblings.

Study 2 : Factors Mediating Subject/Proxy Concurrence in QOL Ratings among Subjects with ID and Non-disabled Proxies.

Aim and Hypotheses

Study 2 replicated Study 1 except that concurrence between non-disabled proxies and subjects with ID was investigated and ComQol-ID4, an adaptation of ComQol-A4, was used. The results of Study 1 indicated that the selected factors had minimal impact on concurrence, thus it was expected that similar effects would be found for Study 2. In contrast to the findings of Study 1, a lower degree of subject/proxy concurrence was expected because, in line with previous studies involving subjects with ID, it was anticipated that ID might constitute a significant barrier to concurrence, affecting the overall agreement between proxies and their subjects. However, due to differences between the scale values for Subjective QOL on ComQol-A4 and ComQol-ID4, direct statistical comparisons were not attempted. Hypotheses similar to those for Study 1 were pursued in relation to the four demographic factors and one psychological factor predicted to affect subject/proxy concurrence.

Method

Participants

A total of 24 subjects participated, all of whom were clients registered with Intellectual Disability Services, a sub-program of the Tasmanian Department of Community and Health Services. All had mild intellectual disability, i.e. an IQ between 50 and 70 (American Psychiatric Association, 1994), determined at the time of their registration with the Department. There were 12 males and 12 females, ranging in age from 18 to 56 years ($M = 30$ years 4 months, $SD = 12$ years 11 months). Of these participants, 9 had completed up to Grade Ten in special education programmes, 13 had completed Grade Twelve in special education programmes and 2 held a TAFE certificate from a 'life skills' course. All subjects were able to legibly sign their own name, accurately report their gender, age, date of birth and street address.

Study 2 was designed as a replication of Study 1, and focused on family members as proxies. However, many of the subjects with ID had lost contact with their families. Subsequently it was necessary to involve support staff in the proxy role, based on the understanding that they were acting in the role of *loco parentis*. Therefore, proxies were either parents ($n=8$) or support workers ($n=16$). There were 3 male and 21 female proxies giving rise to 13 same sex and 11 opposite sex subject/proxy pairs. Proxies ranged in age from 28 to 79 years ($M = 45$ years 8 months, $SD = 14$ years 11 months). The length of association between subjects and proxies ranged from 1 to 48 years, ($M = 12$ years 5 months, $SD = 14$ years 6 months), with 6 proxies reporting that they lived with their respective subjects and 18 reporting that they lived separately. A

total of 8 proxies reported being in daily contact with their respective subjects, 7 on a weekly basis and 9 at least monthly.

Instrumentation

As with Study 1, subjects' QOL was assessed using the ComQol and proxies completed both a ComQol and the MEEQ. However, a parallel version of ComQol-A4, incorporating a structured interview for people with ID, was used (ComQol-ID4, Cummins, 1993). The ComQol-ID4 incorporates a pre-test protocol to establish if the respondent can validly complete subjective ratings. If respondents successfully complete the pre-test protocol, they are provided with a pictorially-based Likert scale to elicit Subjective QOL responses. The Likert scale ranges from two to five points depending upon the subject's performance on the pre-test protocol.

Procedure

Potential participants with ID were identified with the assistance of State Disability Services. Case managers gained consent from these people to release their contact details, allowing contact to be made by the interviewer at the participants' homes. Prior to commencing data collection, a brief explanation of the investigation was given, augmented by a series of COMPIC pictographs (Appendix 2). Participants with ID were then asked to sign a pictograph-based consent form. They were also asked to nominate a family member (non-disabled) whom they believed knew them well enough to tell the interviewer about *'things they owned, things that made them happy and things that made them sad'*. Where a family member was not available, the person was asked to nominate another individual who was well known to them.

Invariably, this person was a support worker. Participants with an ID then underwent the *Test for Discriminative Competence*, which is part of ComQol-ID4. All participants satisfied the criterion required for use of the five-point Likert scale. ComQol-ID4 was then administered according to the directions in the manual.

Proxies were contacted either in person or by telephone, and a standard explanation of the project was given. Proxies were provided with a copy of the ComQol-ID4 and requested to answer the questions, as they believed their relative (or client in the case of support workers) would answer. Instead of pictograph scales, proxies used numerical-based Likert Scales and the focus questions asked proxies about how they believed their family member (or client) would rate the item in question. Otherwise, the ComQol questionnaires were identical. Forms were coded to identify corresponding subjects and proxies. A reply-paid envelope was provided and return of the questionnaire was accepted as consent to participate.

Results

Concurrence Scores

As for Study 1, the dependent variable investigated in this study was concurrence between subject and proxy ComQol ratings. Concurrence was expressed as the degree of discrepancy between subject and proxy ratings. This measure was calculated for the Objective and Subjective domains as for Study 1. The possible range of concurrence of Objective QOL was the same as for Study 1, ranging from 0 to 84 (i.e., 7 sub-scales x maximum discrepancy of 12 on each sub-scale). For Subjective QOL, the rating range for Satisfaction was 1 to 5, as for the ComQol-A4

used in Study 1. However, the possible rating of Importance was reduced to a range of 1 to 5, compared with the range of 1 to 7 for ComQol-A4 in Study 1. Therefore, in Study 2 the maximum discrepancy between subject and proxy pairs on each of the seven Subjective sub-scales was 24 and subsequently the possible range of Subjective concurrence was 0 to 168 (i.e., 7 sub-scales x maximum discrepancy of 24 on each sub-scale).

Analysis

Five-factor ANOVAs used in Study 1 were inappropriate for the present analysis because of the comparatively small size of the sample ($N = 24$ subject/proxy pairs) and would have produced a large number of empty cells in the analysis. Therefore, five unrelated samples *t*-tests were performed, with the demographic and psychological variables employed as the grouping factors. These variables were Proxy Living Arrangements (co-habitation with subject or living separately), Proxy Relationship (parent or sibling), Proxy Gender (male or female), Subject / Proxy Gender Similarity (same or different) and Proxy Empathy (high or low empathy). High and low empathy groups were established by a median split in the ranked MEEQ ratings of proxies. For Study 2, the high empathy group had scores equal to or greater than 44 and the low empathy group had scores less than 44. For means and standard deviations, see Appendix 4.

For all analyses alpha was set at .05. A Bonferroni correction was not considered appropriate as the analyses were based on a relatively small numbers of cases and its use may have given rise to Type 2 errors, i.e. a failure to detect significant effects.

Factors Influencing Concurrence for Objective QOL

Results from *t*-tests for the Objective QOL indicated no significant differences between concurrence scores for analyses involving all five independent variables. The mean concurrence scores for Objective QOL suggest only minimal differences (see Table 6 for means and standard deviations). Furthermore, mean concurrence scores are at the high end of the range of possible concurrence for Objective QOL (0 to 84). Standard deviations indicate little variability in the individual concurrence scores contributing to the means.

Table 6.
Mean concurrence scores for Objective QOL ratings by 24 subject/proxy pairs.

Independent Variables		<i>n</i>	<i>M</i>	<i>SD</i>
Living Arrangements	- with subject	6	66.50	8.74
	- separately	18	68.78	3.52
Proxy Relationship	- parent	8	67.37	7.56
	- other	16	68.63	3.73
Proxy Gender	- male	3	71.33	8.51
	- female	21	67.76	4.68
Proxy/Subject Gender	- same	13	67.23	6.31
	- opposite	11	69.36	3.33
Proxy Empathy	- low	13	66.39	6.33
	- high	11	70.36	2.01

Note : Possible range of concurrence = 0 to 84

Factors Influencing Concurrence for Subjective QOL

Results from unrelated samples *t*-tests for the Subjective QOL indicated no significant differences between concurrence scores in the analyses pertaining to the five independent variables. Mean concurrence scores for Subjective QOL indicate only minimal differences between subject and proxy ratings (see Table 7 for means and standard deviations). Moreover, mean concurrence scores are all high in relation to the possible range of concurrence (0 to 168) and standard deviations indicate that variability in the individual concurrence scores was not great.

Table 7.

Mean concurrence scores for Subjective QOL ratings by 24 subject/proxy pairs.

Independent Variables		<i>n</i>	<i>M</i>	<i>SD</i>
Living Arrangements	- with subject	6	123.17	22.45
	- separately	18	118.11	19.29
Proxy Relationship	- parent	8	117.13	22.03
	- sibling	16	125.50	19.16
Proxy Gender	- male	3	126.00	29.61
	- female	21	118.43	18.79
Proxy/Subject Gender	- same	13	119.23	20.07
	- opposite	11	119.55	20.31
Proxy Empathy	- low	13	125.15	19.14
	- high	11	112.54	19.03

Note : Possible range of concurrence = 0 to 168

Over or Underestimation of Subject QOL Ratings by Proxies

Given the comparatively high degree of subject/proxy concurrence and consequently the possible utility of proxy-based QOL data, the significance of the difference and the direction of the relationship between subject and proxy QOL ratings were investigated. Unrelated samples *t*-tests were conducted on mean subject and proxy ratings of Objective and Subjective QOL to investigate whether proxies significantly overestimated or underestimated the QOL ratings made by their subjects. These findings indicated that Proxy ratings of Objective QOL ($M = 8.76$, $SD = 1.10$) underestimated subject ratings ($M = 9.24$, $SD = 1.45$), though not to a significant degree; $t(23) = 1.55$, $p = .14$. For Subjective QOL, proxies' mean ratings of importance ($M = 3.64$, $SD = 0.45$) did not significantly differ from subjects' mean ratings ($M = 3.82$, $SD = 0.71$); $t(23) = 1.20$, $p = .24$. Similarly, proxies' mean ratings of satisfaction ($M = 4.57$, $SD = 1.07$) did not significantly differ from subjects' mean ratings ($M = 4.52$, $SD = 0.93$); $t(23) = 0.26$, $p = .80$. Furthermore, for both subjects and proxies mean ratings approached the scale maximum for Objective QOL (i.e., 15) and Subjective QOL, on both ratings of importance (i.e., 5) and satisfaction (i.e., 5).

Discussion

This study investigated the possible effects of one psychological and four demographic variables on the concurrence of QOL ratings between subjects with ID and non-disabled proxies, utilising the ComQol-ID4. For the Objective domain, results showed a high degree of subject/proxy concurrence for Objective QOL, regardless of the characteristics of the proxies concerned. In the absence of

significant effects there was insufficient evidence to support of any of the hypotheses relating to the possible effects of subject/proxy living arrangements, relationships, gender and proxy empathy on subject/proxy concurrence for ratings of Objective QOL.

Similarly, for the Subjective domain, the results showed a comparatively high degree of subject/proxy concurrence with no significant differences between subject and proxy ratings of QOL. Again, there was insufficient evidence to support of any of the hypotheses relating to the possible effects of factors pertaining to proxies and subjects.

The present results, showing high levels of concurrence, support the use of proxy based measures of QOL for people with ID. However, the comparatively high overall rating of QOL provided by both subjects and proxies may have confounded the findings for factors hypothesised to influence concurrence. A response set in which respondents rated consistently near the top of the scale has been recognised in relation to the ComQol (Cummins, unpublished) and this factor was a major influence on overall ratings, perhaps leaving little room for the operation of external factors such as those investigated in this study. Furthermore, the present measure of concurrence was moderately conservative, and a more stringent measure of concurrence at an item level, rather than at a sub-scale level may have produced different results.

Overview of Studies 1 and 2 and Directions for Future Research

The purpose of this investigation was to examine concurrence between subjects' self-reported quality of life (QOL) and predictions of their QOL made by proxies, who were either a first degree relative or acting in a position of *loco parentis*. Parents' and siblings' predictions in relation to the self-ratings of non-disabled subjects were examined; and in the case of subjects with ID, the predictions of parents and support workers were investigated. Furthermore, the investigation sought to identify factors contributing to the concurrence of subject and proxy ratings. Therefore, the effect of proxy empathy was explored as well as several demographic variables hypothesised to mediate the concurrence of subject and proxy ratings. It was proposed that clarification of the effect of such factors would assist in the identification of proxies with characteristics likely to enhance the validity of proxy-based reports concerning the QOL of people with ID. These people by virtue of their disability may be limited in their capacity to provide QOL data relevant to the design, implementation and review of their support services. For this reason, concurrence was investigated first between proxies and non-disabled subjects, and second between proxies and subjects with mild ID who were able to provide QOL ratings.

In both Studies 1 and 2 there was a comparatively high degree of subject/proxy concurrence for measures of Objective and Subjective QOL. These results endorse the use of proxy-based QOL measures with the ComQol. Nevertheless, it was evident that both subject and proxy ratings for Objective and Subjective QOL were clustered around the upper end of the rating scales. This positive response bias is consistent with the observation of Cummins (unpublished) that there is evidence of a

psychological set point for feelings of personal well-being and an observed tendency for respondents to rate QOL at approximately 75% of scale maximum. This phenomena is problematic for the investigation of the factors effecting subject/proxy concurrence. Further large-scale research is required, in which response bias is controlled by removing data that exhibit a high degree of response bias. These measures were not undertaken in the present studies due to their exploratory nature, and because of the critical size of the samples for the analyses that were undertaken.

The comparatively high degree of concurrence found between subject and proxy ratings was comparable to some of the findings of Epstein et al. (1989). However, they were not consistent with the more commonly reported findings of low subject/proxy concurrence previously reported in the literature concerning subjects with a disability (e.g., Burnett, 1989; Rigby, McCarron & Ribby, 1990) and non-disabled subjects (e.g., Andrews & Withey, 1976; Boyle & Brann, 1992; Fikree, Gray & Shah, 1993; Rende & Plomin, 1991). Nevertheless, these studies report a range of investigations using different methodologies and the degree of subject/proxy concurrence appears to vary according to the individual issues under investigation and the specific instruments employed.

Overall there was an absence of significant main effects for any of the variables hypothesised to influence concurrence. These results may indicate that none of the present factors alone affect subject/proxy concurrence. However, the present results may equally have arisen from methodological constraints related to the operation of a response bias in ComQol ratings, and the way in which concurrence was measured.

For this reason, future studies could explore the effect of using a more conservative measure of subject/proxy concurrence, and possibly at an item level.

Some factors appeared to interact in affecting concurrence on Subjective QOL for non-disabled proxies and subjects. Nevertheless, in the absence of specific main effects, it is unlikely that such interactions would be replicated and these findings should therefore be interpreted with caution. Simple effects suggested that for high empathy proxies co-habitation with subjects may enhance concurrence and that gender only influences concurrence under low empathic conditions. In these circumstances males appear to exhibit greater concurrence with non-disabled subjects. Overall the specific effects were isolated and problematic to interpret in terms of their practical implications.

In both studies proxies tended to underestimate subject ratings of Objective QOL and overestimate subject ratings of Subjective QOL. However, statistically significant differences were only evident between subject and proxy ratings for Objective QOL in relation to non-disabled subjects. The magnitude of this result was small, being less than 1 on a scale of 1 to 15. Although statistically significant, such a difference would not be of any practical significance when using ComQol for actual assessments.

The similarity of the findings across the two studies suggests that the presence of ID does not significantly alter the contingencies surrounding proxy responses, but due to the different scalar values for Subjective QOL on the ComQol-A4 and ComQol-ID4

direct comparisons were not attempted. In future studies it would be possible to standardise ComQol data according to the percentage of scale maximum (Cummins, 1993) prior to computation of concurrence scores. Nevertheless, such standardisation may remove the data yet a further step away from the actual ratings. In the present studies this transformation was not undertaken for these reasons. Perhaps a simpler solution to the comparability problem would be to use a similar scale for all respondents, based on the minimum level of scale that could be interpreted by the respondents with ID. Some degree of data richness may be lost in collapsing, for example, a five point scale to a three point scale, but at least direct comparability based on actual responses could be achieved. Furthermore, Study 2 explored subject/proxy concurrence where subjects had only a mild ID. Generalising these findings to subjects with more severe degrees of disability should be approached with caution. The severity of the disability may pose a more formidable barrier to proxy evaluation. Also the sample size for Study 2 was small due to constraints in obtaining suitable participants with ID.

The lack of significant effects from the variables investigated suggests that such basic characteristics as living arrangements and types of subject/proxy relationships may not make a great difference to the validity of proxy predictions of QOL in the case of proxies who know people well (i.e., by being a first degree relative or, in the case of support workers, being in regular contact with subjects). However, such factors may be significant where proxies do not know their subjects well. If proxies are selected on the basis of close relationships it does not seem to matter if they are parents, siblings or support workers, male or female. This finding suggests that it is fairly

straightforward to select proxies for people with mild ID. Some over or underestimation of subject ratings by proxies can be expected, but not to the extent that it affects the practical end uses of proxy QOL data. Therefore, proxy ratings on ComQol can be expected to be a good indicator of how the person himself or herself may respond.

Despite the commonly accepted use of proxy-based data to guide the development of services for people with ID, there remain numerous unanswered questions concerning both the validity and reliability of such an approach. Given the current availability of QOL assessments, further research concerning their appropriate use is essential. Issues requiring investigation include parent versus staff efficacy in predicting client QOL, the possible effects of age differences between proxies and subjects with ID and the extent to which a proxies' ratings of their own QOL may influence their predictions on behalf of a relative or client.

Author Note : In both Studies 1 and 2, to distinguish between the primary respondents and their proxies, the term *subject* has been used to denote primary respondents. While APS publication guidelines suggest the use of the term *participants*, in the current context both subjects and proxies were participants.

References

- American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition : DSM-IV*. Washington, D.C.
- Andrews, F. & Withey, S. (1976). *Social indicators of 'well-being': American's perceptions of life quality*. New York : Plenum Press.
- Barlow, J. & Kirby L. (1991). Residential satisfaction of persons with an intellectual disability living in an institution or the community. *Australian and New Zealand Journal of Developmental Disability*, 17, 7-23.
- Boyle, C., & Brann, E. (1992). Proxy respondents and the validity of occupational and other exposure data. *American Journal of Epidemiology*, 136, 712-721.
- Burnett, P. (1989). Assessing satisfaction in people with an intellectual disability living in community based residential facilities. *Australian Disability Review*, 1, 14-19.
- Chun Yu, A., Jupp, J. & Taylor, A. (1996). The discriminate validity of the Lifestyle Satisfaction Scale (LSS) for the assessment of Australian adults with intellectual disabilities. *Journal of Developmental and Intellectual Disability*, 21, 3-15.
- Cummins, R. (1993). *Comprehensive Quality of Life Scale (ComQol) Fourth Edition*. Toorak, Australia : School of Psychology, Deakin University.
- Cummins, R. (unpublished paper). *On the trail of the gold standard for subjective well-being*. Toorak, Australia : School of Psychology, Deakin University.
- Cummins, R., McCabe, M., Romeo, Y. & Gullone, E. (1994). The Comprehensive Quality of Life Scale: Instrument development and psychometric evaluation on college staff and students. *Educational and Psychological Measurement*, 54, 372-382 .
- Davey, V. & Pitfield-Smith, S. (1990). *A model for wholistic evaluation*. Adelaide, Australia : Barkuma Incorporated.
- Davey, V. & Pitfield-Smith, S. (1992). *Wholistic Evaluation: an evaluation package developed by Barkuma Inc. for the review of residential programs*. Adelaide, Australia : Barkuma Incorporated.
- Emerson, E. & Hatton, C. (1996). Deinstitutionalisation in the UK and Ireland : outcomes for service users. *Journal of Developmental and Intellectual Disability*, 21, 17-39.
- Epstein, A., Hall, J., Tognetti, J., Son, L. & Conant, L. (1989). Using proxies to evaluate quality of life. *Medical Care*, 27, 91-98.

- Evans, G., Felce, D. & Hobbs, S. (1991). *Evaluating Service Quality*. Cardiff, UK: S.C.O.V.O.
- Felce, D. & Perry, J. (1993). *Quality of life: a contribution to its definition and measurement*. Cardiff, UK: Welsh Centre for Learning Disabilities.
- Fikree, F., Gray, R. & Shah, F. (1993). Can men be trusted? A comparison of pregnancy histories reported by husbands and wives. *American Journal of Epidemiology*, 138, 237-242.
- Fogarty, D. & Cummins, R. (1994). *Quality of life bibliography*. Melbourne, Australia : School of Psychology, Deakin University.
- Fontana, A., Marcus, J., Dowds, B. & Hughes, L. (1980). Psychological impairment and psychological health in the psychological well-being of the physically ill. *Psychosomatic Medicine*, 42, 279-288.
- Halabi, S., Zurayk, H., Awaida, R., Darwish, M.. & Saab, B. (1992). Reliability and validity of self and proxy reporting of morbidity data. *International Journal of Epidemiology*, 21, 607-612.
- Kanouse, D. & Hanson, L. (1972). Negativity in evaluations, In E. Jones (Ed.) *Attribution: perceiving the causes of behaviour*. Morristown, NJ: General Learning Press.
- McCusker, J. & Stoddard, A. (1984). Use of a surrogate for the Sickness Impact Profile. *Medical Care*, 22, 789-795.
- McVilly, K. (1995). Interviewing people with a learning disability about their residential service. *British Journal of Learning Disabilities*, 23, 138-142.
- Mehrabian, A. & Epstein, N. (1972). A measure of emotional empathy. *Journal of Personality*, 40, 525-543.
- Nevitt, M., Cummins, S., Browner, W., Seeley, D., Cauley, J., Vogt, T. & Black, D. (1992). The accuracy of self-report of fractures in elderly women : evidence from a prospective study. *American Journal of Epidemiology*, 135, 490-499.
- Parmenter, T. (1992). Quality of life of people with developmental disabilities. *International Review of Research in Mental Retardation*, 18, 247-287.
- Rende, R. & Plomin, R. (1991). Child and parent perceptions of the upsettingness of major life events. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 32, 627-633.
- Rigby, K., McCarron, L. & Ribby, J. (1990). *Quality of life in a nursing home: a report on the perceptions of residents and staff at Julia Farr Centre*. Adelaide, Australia: South Australian Institute of Technology.

Rowitz, L. (1989). Editorial: Trends in mental retardation in the 1990s. *Mental Retardation*, 27, iii-vi.

Schallock, R. (1989). *Services for developmentally disabled adults - development, implementation and evaluation*. Baltimore : University Park Press.

Appendices

Appendix 1.

ComQol-A4 and attachments, as used in Study 1. p. i

Appendix 2.

ComQol-ID4 and attachments, as used in Study 2. p. xii

Appendix 3.

MEEQ as used by proxies in Studies 1 & 2. p. xxxvii

MEEQ means, standard deviations and rating ranges
for Studies 1 & 2. p. xlvii

Appendix 4.

ANOVA Tables relating to Study 1. p. xlvii

Appendix 1.

ComQol-A4 and attachments, as used in Study 1.

Note : Subjects and their proxies were provided with the same information sheet and used the same questionnaire. However, copies of ComQoL-A4 for use by proxies were adapted by modifying the cover sheet and adding the BOLD instructions found at the head of each section.

The involvement of family members in evaluating Quality of Life

Keep this sheet for your reference

You have been invited to participate in a research project. Its aim is to determine the characteristics of people best suited to provide information concerning the quality of life experienced by a family member. The project is being conducted as part of a Masters' Thesis in the Department of Psychology at the University of Tasmania. Data from the project will contribute to the development of processes designed to support people with disabilities.

All information is completely anonymous. Your participation is voluntary; you may withdraw at any time without prejudice to any course you / your family member may be undertaking or service you / your family member may receive.

To participate you will need to do the following :

- 1] Complete the **green** questionnaire concerning *your own* quality of life and some associated issues. This should take no more than 30 minutes;
- 2] Complete the **blue** questionnaire concerning how *you* think *your brother or sister* (who is also participating in this project) would rate *their own* quality of life;
- 3] Ask one parent to complete the **yellow** questionnaire concerning how *they* think *you* would rate *your own* quality of life;
- 4] Return the questionnaires to the University in the envelopes provided.

Questionnaires to be returned by _____

It is very important that you and your family members complete the questionnaires independently. If you or your family members have any doubts about a question, answer with 'a best guess'. Do not compare notes or ask anyone for help. If, having completed the questionnaires, you choose to compare notes, **do not** under any circumstances alter the results, no matter how similar or different, accurate or inaccurate, they may appear to be.

This project has received approval from the University of Tasmania Ethics Committee (Human Experimentation) and complies with all relevant legislation, both State and Commonwealth. If you have any questions regarding the project, please feel free to contact either Rosanne Rawlinson (PH : 202237) or Keith McVilly (PH : 338830). If you have any concerns of an ethical nature or complaints regarding the procedure, please contact the University of Tasmania Ethics Committee (PH : 202763).

Data from the project may be published. However, no individual or identifying information will be released. Participants are welcome, from December, to seek information concerning the overall findings.

Keith R. McVilly,
Post Graduate Research Student
University of Tasmania

Rosanne Rawlinson,
Lecturer / Supervisor
University of Tasmania

ComQol-4

My relationship to the person about whom I am completing this form is (circle one) :

MOTHER / FATHER / SISTER / BROTHER / FRIEND / SUPPORT
WORKER / OTHER (please describe) _____

n.b. Spouses / Partners are intentionally excluded from this survey

My age is : _____ years.

I am (circle one) : Male / Female

My highest educational attainment has been (circle one) :

Primary / Leavers' Certificate / Higher School Certificate /
TAFE or Trades Certificate / University Degree

I, myself, have a disability (circle one) ? : YES / NO

If YES, Please briefly describe any disability : _____

I have known the person who gave me this form for : _____ years

I live in the same house as them (circle one) : YES / NO

I have contact with them (circle one) :

daily / 2-3 per week / weekly / fortnightly / monthly / less than
once a month (if so, please state - _____)

Reference No. _____

SECTION 1 : Please answer the following questions about your family member, friend or client. If in doubt, give it your *best guess* but do not actually ask the person concerned. We need your response.

- 1 a) What is your personal or household (whichever is most relevant to you) gross annual income before tax?

Less than \$10,999 ☐

\$41,000 - \$ 55,999 ☐

\$11,000 - \$25,999 ☐

More than \$56,000 ☐

\$26,000 - \$40,999 ☐

- b) Where do you live?

A house, flat or apartment of :

Which best describes who you live with:

- High quality ☐

- alone, family, close friend ☐

- Medium quality ☐

- 1 or 2 acquaintance(s) ☐

- Low quality ☐

- 3 or more acquaintances ☐

or Hostel ☐

- c) How many personal possessions do you have compared with other people?

More than
almost anyone

☐

More than
most people

☐

About
average

☐

Less than
most people

☐

Less than
almost anyone

☐

- 2 a) How many times have you been to the doctor over the past 3 months?

Number of times _____

- b) Do you have any disabilities or medical conditions? (e.g. visual, hearing, physical, health, etc.).

Yes ☐ No ☐

If "yes please specify:

Name of disability
or medical condition

Extent of disability
or medical condition

e.g. Visual
Diabetes

Require glasses for reading
Require daily injections

- c) What regular medication do you take each day?

If none tick box ☐

OR

Name(s) of medication

- 3 a) How many hours paid work, formal education, or unpaid child care do you do each week? (Average over past 3 months)

Hours paid work _____ Hours formal education _____

Hours unpaid child care _____

- b) In your spare time, how often do you have nothing much to do?

Almost
always

Usually

Sometimes

Not usually

Almost
never

☐
☐
☐
☐
☐

- c) Over the past week, list the most productive things you have done. These can include anything you have made, collected, performed, created, mended, or any voluntary work.

None ☐ (tick)

OR

Description

Over how many days in the week did this happen?

4. a) How often do you talk with a close friend?

Daily	Several times a week	Once a week	Once a month	Less than once a month
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- b) If you are feeling sad or depressed, how often does someone show they care for you?

Almost always	Usually	Sometimes	Not usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- c) If you want to do something, how often does someone else want to do it with you?

Almost always	Usually	Sometimes	Not usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5 a) How often do you sleep well?

Almost always	Usually	Sometimes	Not usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

b) Is your home a safe place to be?

Almost always	Usually	Sometimes	Not usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

c) How often do you feel worried or anxious during the day?

Almost always	Usually	Sometimes	Not usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6 a) Below is a list of activities. Indicate how often in an average month you do each one.

Activity	Number of times per month
(1) Clubs/groups/societies (please provide the name <u>as well</u> <u>as</u> the number of times you attend each month).	<hr/> <hr/>
(2) Hotel/Bar	<hr/>
(3) Watch live sporting events (Not on TV)	<hr/>
(4) Church	<hr/>
(5) Chatting with neighbours	<hr/>
(6) Restaurant	<hr/>
(7) Movies	<hr/>
(8) Other (describe)	<hr/> <hr/>

- b) Do you hold a position of responsibility in relation to any club, group, or society?

Yes ☐ No ☐

If yes, please describe.

- c) How often do people outside your home ask for your help or advice?

Almost
every day

☐

Quite often

☐

Sometimes

☐

Not
often

☐

Almost never

☐

- 7 a) How often can you do the things you really want to do?

Almost
always

☐

Usually

☐

Sometimes

☐

Not
usually

☐

Almost never

☐

- b) When you wake up in the morning, how often do you wish you could stay in bed all day?

Almost
always

☐

Usually

☐

Sometimes

☐

Not
usually

☐

Almost never

☐

- c) How often do you have wishes that cannot come true?

Almost
always

☐

Usually

☐

Sometimes

☐

Not
usually

☐

Almost never

☐

SECTION 2 : Please answer the following questions as *you* believe your family member, friend or client would answer the questions about themselves. If in doubt, give it your *best guess* but do not actually ask the person concerned.

Please answer by placing a (X) in the appropriate box for each question.

There are no right or wrong answers. Please choose the box that best describes how **important** each area is to you. Do not spend too much time on any one question.

1. How **Important** to you ARE THE THINGS YOU OWN?

Could not be more important	Very important	Somewhat important	Slightly important	Not important at all
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. How **Important** to you is YOUR HEALTH?

Could not be more important	Very important	Somewhat important	Slightly important	Not important at all
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. How **Important** to you is WHAT YOU ACHIEVE IN LIFE?

Could not be more important	Very important	Somewhat important	Slightly important	Not important at all
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. How **Important** to you are CLOSE RELATIONSHIPS WITH YOUR FAMILY OR FRIENDS?

Could not be more important	Very important	Somewhat important	Slightly important	Not important at all
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. How **Important** to you is HOW SAFE YOU FEEL?

Could not be more important	Very important	Somewhat important	Slightly important	Not important at all
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. How **Important to you** is DOING THINGS WITH PEOPLE OUTSIDE YOUR HOME?

Could not be more
important

☐

Very
important

☐

Somewhat
important

☐

Slightly
important

☐

Not important
at all

☐

7. How **Important to you** is YOUR OWN HAPPINESS?

Could not be more
important

☐

Very
important

☐

Somewhat
important

☐

Slightly
important

☐

Not important
at all

☐

SECTION 3 : Please answer the following questions as *you* believe your family member, friend or client would answer the questions about themselves. If in doubt, give it your *best guess* but do not actually ask the person concerned.

There are no right or wrong answers. Please choose the box that best describes how satisfied you are with each area.

1. How Satisfied are you with the THINGS YOU OWN?

Delighted Pleased Mostly satisfied Mixed Mostly dissatisfied Unhappy Terrible

2. How Satisfied are you with your HEALTH?

Delighted Pleased Mostly satisfied Mixed Mostly dissatisfied Unhappy Terrible

3. How Satisfied are you with what you ACHIEVE IN LIFE?

Delighted Pleased Mostly satisfied Mixed Mostly dissatisfied Unhappy Terrible

4. How Satisfied are you with your CLOSE RELATIONSHIPS WITH FAMILY OR FRIENDS?

Delighted Pleased Mostly satisfied Mixed Mostly dissatisfied Unhappy Terrible

5. How Satisfied are you with HOW SAFE YOU FEEL?

Delighted Pleased Mostly satisfied Mixed Mostly dissatisfied Unhappy Terrible

6. How Satisfied are you with DOING THINGS WITH PEOPLE OUTSIDE YOUR HOME?

Delighted Pleased Mostly satisfied Mixed Mostly dissatisfied Unhappy Terrible

7. How Satisfied are you with YOUR OWN HAPPINESS?

Delighted Pleased Mostly satisfied Mixed Mostly dissatisfied Unhappy Terrible

Appendix 2.

ComQol-ID4 and attachments, as used in Study 2.

Note : Subjects were provided with a standard oral introduction to the study, augmented by COMPIC pictographs. Proxies were provided with an information sheet. Both subjects and proxies completed the same questionnaire. However, for subjects the questionnaire was presented as an interview. Also, while subjects' responded by use of a pictograph scale, proxies responded by use of a standard Likert-scale.

Investigating Quality of Life for People with Disabilities

A member of your family or a person otherwise known to you (noted at the end of this letter) has been invited to participate in a survey. They have been asked to answer a number of questions relating to their *quality of life*. To assist with the survey, you too have been invited to complete a short questionnaire based on how you think your family member, friend or client would view certain aspects of their life. Your contribution is essential if we are to get a complete picture of the *quality of life* experienced by people with disabilities.

The questionnaire should take no more than **15-20 minutes** to complete. A free post / reply paid envelope has been enclosed for you to return the survey. Surveys will need to be returned **within 10 days** of their arrival.

It is very important that you complete the enclosed survey as *you* believe your family member, friend or client would answer the questions. However, it is very important that you **do not** actually ask them yourself - simply answer the questions as *you* think they would. If you have any doubts about a question, give it your *best guess*.

All information will be kept confidential. The survey results will be used in a research project currently being conducted by the Department of Psychology at the University of Tasmania. They will also contribute to the development of individual / case management systems currently being piloted by the Disability Services Programme of the Tasmanian Department of Community & Health Services.

If you have any questions concerning this survey you can contact me c/ Disability Services, PH : 338830 or Vocational Rehabilitation Services, PH : 369677.

Thank you for your time and contribution to this research.

Yours faithfully,

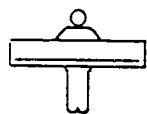
Keith R. McVilly,
Post Graduate Research Student
University of Tasmania

Rosanne Rawlinson,
Lecturer / Supervisor
University of Tasmania

The person about whom you have been asked to complete the questionnaire is :

Statement of Informed Consent

Evaluating quality of life for people with disabilities : the selection of proxy respondents



I have had



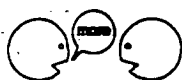
the information sheet



explained to me



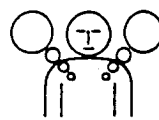
I know that



I will be asked



some questions



about my feelings,



things I own,



my health,



things I make,



things I learn,



my friends,



things I do,



when I am scared,



when I am happy.



I know that



what I say



will be written down



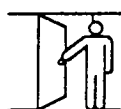
and be a secret.



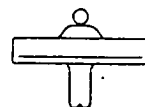
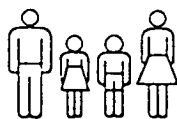
I know that



I can stop



and leave at any time

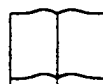


I know that

my family

will be asked questions

about me



I know that ~~some~~ things will be written down

and put in a book.



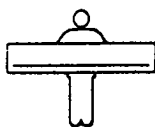
All my questions

have been answered



I am happy

to participate



Signed

I have explained this project and the implications of participation in it to this volunteer and I believe that the consent is informed and that s/he understands the implications of participation.

Keith R. McVilly, Investigator.

Date

ComQol-ID4

FOURTH EDITION

"I am going to ask some questions about your life. [Carer] can help you at the start. Later I will ask you to answer some questions by yourself. Is that OK?"

"If you do not understand a question, just let me know."

Your name

(Please print)

Date of Birth

____/____/____

Day Month Year

Sex (circle one)

male

female

I am (circle one) : Male / Female

My age is : _____ years.

My place in the family is (e.g. First born) : _____

My highest educational attainment has been (circle one) :

Primary / Leavers' Certificate / Higher School Certificate /
TAFE or Trades Certificate / University Degree

Do you have a disability of any kind (circle one) ? : YES / NO

If YES, Please briefly describe any disability : _____

SECTION 1: This section asks for information about various aspects of your life. Please mark the box that most accurately describes your situation.

- 1 a) What is your personal or household (whichever is most relevant to you) gross annual income before tax?

Less than \$10,999 ☐

\$41,000 - \$55,999 ☐

\$11,000 - \$25,999 ☐

More than \$56,000 ☐

\$26,000 - \$40,999 ☐

- b) Where do you live?

A house, flat or apartment of :

Which best describes who you live with:

- High quality ☐

- alone, family, close friend ☐

- Medium quality ☐

- 1 or 2 acquaintance(s) ☐

- Low quality ☐

- 3 or more acquaintances ☐

or Hostel ☐

- c) How many personal possessions do you have compared with other people?

More than
almost anyone

☐

More than
most people

☐

About
average

☐

Less than
most people

☐

Less than
almost anyone

☐

- 2 a) How many times have you been to the doctor over the past 3 months?

Number of times _____

- b) Do you have any disabilities or medical conditions other than an intellectual disability? (e.g. visual, hearing, physical, health, etc.).

Yes ☐ No ☐

If "yes" please specify:

Name of disability
or medical condition

Extent of disability
or medical condition

e.g. Visual
Diabetes

Require glasses for reading
Require daily injections

- c) What regular medication do you take each day?

If none tick box ☐

OR

Name(s) of medication

- 3 a) How many hours paid work, formal education, or unpaid child care do you do each week? (Average over past 3 months)

Hours paid work _____ Hours formal education _____

Hours unpaid child care _____

- b) In your spare time, how often do you have nothing much to do?

Almost
always

Usually

Sometimes

Not usually

Almost
never

☐

☐

☐

☐

☐

- c) Over the past week, list the most productive things you have done. These can include anything you have made, collected, performed, created, mended, or any voluntary work.

None ☐ (tick)

OR

Description

Over how many days in the week did this happen?

4. a) How often do you talk with a close friend?

Daily	Several times a week	Once a week	Once a month	Less than once a month
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- b) If you are feeling sad or depressed, how often does someone show they care for you?

Almost always	Usually	Sometimes	Not usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- c) If you want to do something, how often does someone else want to do it with you?

Almost always	Usually	Sometimes	Not usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5 a) How often do you sleep well?

Almost
always

☐

Usually

☐

Sometimes

☐

Not
usually

☐

Almost never

☐

b) How often do you feel safe at home?

Almost
always

☐

Usually

☐

Sometimes

☐

Not
usually

☐

Almost never

☐

c) How often do you feel worried or anxious during the day?

Almost
always

☐

Usually

☐

Sometimes

☐

Not
usually

☐

Almost never

☐

6 a) Below is a list of activities. Indicate how often in an average month you take part in or attend each one.

Activity

Number of times per month

- (1) Clubs/groups/societies
(please provide the name as well
as the number of times you
attend each month).

- (2) Go to Hotel/Bar

- (3) Watch live sporting events
(Not on TV)

- (4) Go to Church

- (5) Chat with neighbours

- (6) Go to Restaurant

- (7) Go to a Movie

- (8) Other (describe)

- b) Do you hold a position of responsibility in relation to any club, group, or society?

Yes ☐ No ☐

If yes, please describe.

- c) How often do people outside your household ask for your help or advice?

Almost
every day

☐

Quite often

☐

Sometimes

☐

Not
often

☐

Almost never

☐

- 7 a) How often can you do the things you really want to do?

Almost
always

☐

Usually

☐

Sometimes

☐

Not
usually

☐

Almost never

☐

- b) When you wake up in the morning, how often do you wish you could stay in bed all day?

Almost
always

☐

Usually

☐

Sometimes

☐

Not
usually

☐

Almost never

☐

- c) How often do you have wishes that cannot come true?

Almost
always

☐

Usually

☐

Sometimes

☐

Not
usually

☐

Almost never

☐

2.2 Client Testing For Discriminative Competence

The purpose of the following procedures is to establish whether the client is able to independently respond to the subjective components of the scale. While the primary caregiver may remain during this testing the client must respond to the following tasks without assistance.

The testing moves through three phases which are designed to determine whether the client can:

- A) identify items in order of magnitude,
- B) use a scale with a concrete reference,
- C) use a scale with an abstract reference.

The testing protocol moves responding from concrete to abstract. Within each of the three testing phases the tasks progress in complexity from binary choice to a choice involving seven elements.

When the client makes an error, remove the blocks, arrange in a different order, and repeat the question. If the client fails again proceed no further with that phase and move onto the next. The client must respond correctly, at least using the binary choice, in order to proceed to the next phase. If the client is unable to respond correctly to all three testing phases at least at the level of a binary choice, they should not be requested to complete the subjective scale.

The client responds to the questions by pointing.

During testing, the client should be seated at a table and the blocks presented in a row in front of the client. The fact that the blocks are arranged horizontally and the scales are vertical deliberately forces the need for spatial transpositional skills and avoids responding based on spatial copying.

Provided that the client is able to successfully complete each phase of this pre-testing, he or she may progress to the subjective ComQol-ID subscale. The following should be noted:

(a) The level of choice provided in the importance subscale should be determined by the maximum level of discriminative competence displayed during the third phase which used the concept of 'importance'. That is, if a client was able to complete phase (C) at the level of a three-point choice, then subsequent testing on importance will also use a three-point choice.

(b) The subjective questions should not be asked in the presence of the primary carer.

EQUIPMENT

Five wooden, unpainted cubes are required of the following side-length: 2.1 cm, 3.2 cm, 4.3 cm, 5.4 cm, 6.5 cm.

TESTING PROCEDURE

Ask the carer and client to name some possession which the client regards as highly important. This will be used in the third phase of testing.

Item of importance _____

2.2.1. Order of magnitude test

- a) Present client with 2 blocks of extreme different sizes (large = 7, small = 1).

Record of client
Success (✓) or
Failure (x)

Q: Please point to the BIGGEST block.

Q: Please point to the SMALLEST block.

☐

- b) Present 3 blocks of differing sizes and arrange in following order: (small, large, middle)

Q: Please point to the BIGGEST block.

Q: Please point to the MIDDLE SIZED block.

Q: Please point to the SMALLEST block.

☐

Note: If the client makes an error with (b), repeat (a) with the blocks in reverse order to the first trial (i.e. small, large).

- c) Present 5 blocks of differing sizes and arrange in following order: (second smallest, largest, smallest, middle, second largest).

Q: Please point to the BIGGEST block.

Q: Please point to the SMALLEST block.

Q: Please point to the MIDDLE SIZED block.

Q: Please point to the SECOND BIGGEST block.

Q: Please point to the SECOND SMALLEST block.

☐

2.2.2 Scale with a concrete reference

Note: Scales are provided on the following page.

Procedure: Present a 2-point ladder scale. Explain that the top is BIG and the bottom is small. Point to each block when asking the questions.

- a) Present 2 blocks of extreme size difference.

Record of Client
Success (✓) or
Failure (x)

Q: Where does the big block go on the ladder?
(client to point to place on the ladder)

☐

Q: Where does the small block go on the ladder?

☐

- b) Present a 3-point ladder scale and explain each point.

Present 3 blocks in order of size.

Q: Where does the middle-size block go on the ladder?
(client to point to place on the ladder)

☐

- c) Present a 5-point ladder scale and explain each point.

In each of the following say: "Where does this block go on the ladder?"

Present 5 blocks in order of size and point to them in the sequence indicated.

The biggest block.

☐

The middle-size block.

☐

The second biggest block.

☐

The second smallest block.

☐

The smallest block.

☐

2.2.3 Scale with an abstract reference

Note: Scales are provided at the back of this section.

Procedure:

Record of Client
Success (✓) or
Failure (x)

a) Present a 2-point ladder of importance.

- Explain the divisions

- Recall the personal possession that is important to the client (from carer questionnaire). Then ask to place this on the scale.
- Ask "Isvery important to you?"
- Ask "Where would you put it on this ladder?"
- Ask "If something was not important to you where would you place it on the ladder?"

☐

b) Present a 3-point ladder of importance.

- Explain divisions.

Q: If something was very important, where would you put it on the scale?

Q: Not important.

Q: Somewhat important.

☐

c) Present a 5-point ladder of importance.

- Explain divisions.

Q: If something was most important in the world where would you point?

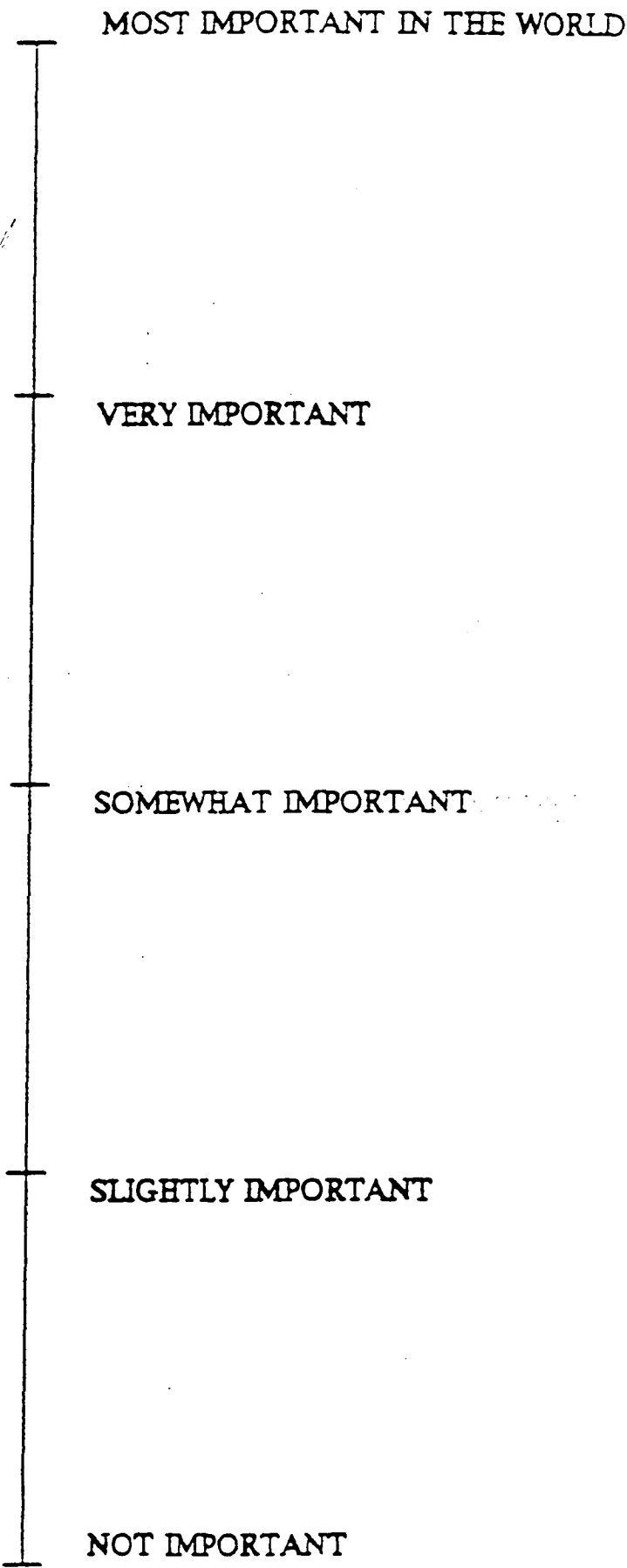
Q: Not important.

Q: Somewhat important.

Q: Slightly important.

Q: Very important.

☐



2.3 Testing of Domain Importance

Procedure: Test the client alone if possible.

- Use the 2, 3 or 5-point importance scale as determined from 2.2.3.

Note: Record the level of scale complexity:

☐

- Explain that the client is now going to be asked how important some things are to them using the 'IMPORTANCE LADDER'.

Each question begins with "How important to you is/are ..."

	<u>Response</u>
1. the things you have? Like the money you have and the things you own.	_____
2. your health? Whether you are sick or not.	_____
3. the things you make or the things you learn?	_____
4. having a close friend or family?	_____
5. how safe you feel?	_____
6. doing things with people outside your home?	_____
7. your own happiness?	_____

2.4.2 Testing of Domain Satisfaction

Note: Faces scales are provided on the following three pages.

Interviewer: Now I want you to do a different job. It's another pointing job, but this time there are 2 faces.

Record of Client
Success (✓) or
Failure (x)

- a) One is a happy face (point), one is a sad face (point).

What makes you happy?

Reply - X

So if I said "How happy are you about X?", which face would you point to?

☐

What makes you sad?

Reply - Y

So if I said "How sad are you about Y?", which face would you point to?

☐

[After establishing that the respondent is able to use the faces appropriately, the interviewer proceeds to the 3-face scale].

- b) Interviewer to explain very happy, very sad and a face that is neither happy nor sad.

Q: If you felt very happy about X which face would you point to?

Q: If you felt very sad about Y which face would you point to?

Q: If you felt neither happy nor sad which face would you point to?

☐

[Move to the 5-faces scale]

- c) Interviewer to explain "happy" and "sad".

Q: If you felt very happy about X which face would you point to?

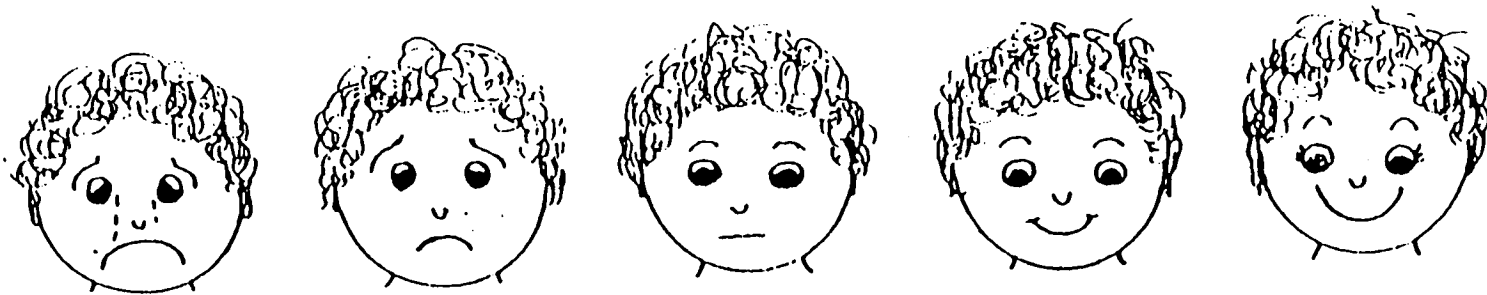
Q: If you felt a bit happy about X.

Q: Very sad.

Q: A bit sad.

Q: Neither happy nor sad.

☐



[After choosing the appropriate scale proceed with questions 1-7]

- Use 2, 3 or 5 point 'happiness' scale as previously determined

Note: Record Point scale used:

☐

Each question begins with: "How happy or sad do you feel about ..."

Response

- | | | |
|----|--|-------|
| 1. | the things you have? Like the money you have, the things you own, and stuff like that. | _____ |
| 2. | your health? Whether you are sick or not. | _____ |
| 3. | the things you make or the things you learn? | _____ |
| 4. | your friends or family? | _____ |
| 5. | how safe you feel? | _____ |
| 6. | doing things outside your home? | _____ |
| 7. | yourself? | _____ |

IMPORTANCE

Statement: "I am going to ask you how IMPORTANT you think some aspects of life are to (client). To do this I want you to answer as though you were (client). That is, the answers that you give should be the answers that you think (client) would give. OK?"

[Provide the vertical IMPORTANCE scale to carer and describe its construction.]

"So, I am now going to name some aspects of life and you will tell me how IMPORTANT each one is for (client)."

[When sure that the task is understood proceed. The carer holds the vertical scale. The tester marks responses onto the scales below.]

1. How Important to (client) ARE THE THINGS he/she OWNS?

Could not be more
important

☐

Very
important

☐

Somewhat
important

☐

Slightly
important

☐

Not at all
important

☐

2. How Important to (client) is his/her HEALTH?

Could not be more
important

☐

Very
important

☐

Somewhat
important

☐

Slightly
important

☐

Not at all
important

☐

3. How Important to (client) are the THINGS he/she MAKES OR THE THINGS he/she LEARNS?

Could not be more
important

☐

Very
important

☐

Somewhat
important

☐

Slightly
important

☐

Not at all
important

☐

4. How Important to (client) are CLOSE RELATIONSHIPS WITH FAMILY AND FRIENDS?

Could not be more
important

☐

Very
important

☐

Somewhat
important

☐

Slightly
important

☐

Not at all
important

☐

5. How Important to (client) is HOW SAFE he/she FEELS?

Could not be more
important

☐

Very
important

☐

Somewhat
important

☐

Slightly
important

☐

Not at all
important

☐

6. How Important to (client) is DOING THINGS WITH PEOPLE OUTSIDE
his/her HOME?

Could not be more
important

☐

Very
important

☐

Somewhat
important

☐

Slightly
important

☐

Not at all
important

☐

7. How Important to (client) is his/her OWN HAPPINESS?

Could not be more
important

☐

Very
important

☐

Somewhat
important

☐

Slightly
important

☐

Not at all
important

☐

SATISFACTION

Statement: "Now I want to ask you a different set of questions. This time I will ask you how SATISFIED you think (client) is with each of the life areas. I still want you to answer as though you were (client). OK?"

[Provide SATISFACTION scale to carer and describe its construction.]

"So, I am now going to name the same areas of life as before and you will tell me how SATISFIED (client) is with each one."

[When sure that the task is understood proceed. The carer holds the vertical scale. The tester marks responses on to the scales below.]

1. How Satisfied is (client) with the THINGS he/she OWNS?

Delighted

☐

Pleased

☐

Mixed

☐

Unhappy

☐

Terrible

☐

2. How Satisfied is (client) with his/her HEALTH?

Delighted

☐

Pleased

☐

Mixed

☐

Unhappy

☐

Terrible

☐

3. How Satisfied is (client) with the THINGS he/she MAKES OR THE THINGS he/she LEARNS?

Delighted

☐

Pleased

☐

Mixed

☐

Unhappy

☐

Terrible

☐

4. How Satisfied is (client) with his/her CLOSE RELATIONSHIPS WITH FAMILY AND FRIENDS?

Delighted

☐

Pleased

☐

Mixed

☐

Unhappy

☐

Terrible

☐

5. How Satisfied is (client) with HOW SAFE he/she FEELS?

Delighted

☐

Pleased

☐

Mixed

☐

Unhappy

☐

Terrible

☐

6. How Satisfied is (client) with DOING THINGS WITH PEOPLE OUTSIDE his/her HOME?

Delighted

☐

Pleased

☐

Mixed

☐

Unhappy

☐

Terrible

☐

7. How Satisfied is (client) with his/her OWN HAPPINESS?

Delighted

☐

Pleased

☐

Mixed

☐

Unhappy

☐

Terrible

☐

Appendix 3.

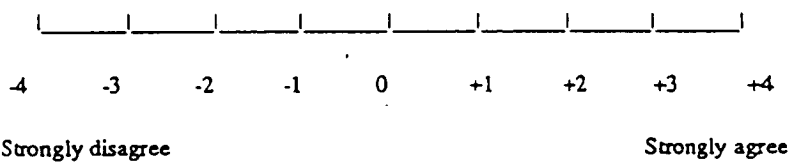
MEEQ as used by proxies in Studies 1 & 2.

MEEQ means, standard deviations and rating ranges for Studies 1 & 2.

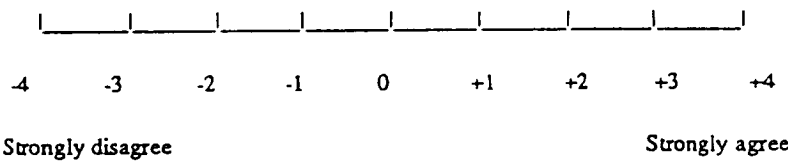
Emotions Questionnaire

Please carefully read each item on the questionnaire and respond to it by circling the appropriate answer on a +4 (very strong agreement) to -4 (very strong disagreement) scale provided under each item.

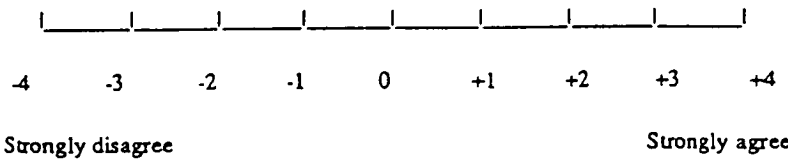
1. It makes me sad to see a lonely stranger in a group.



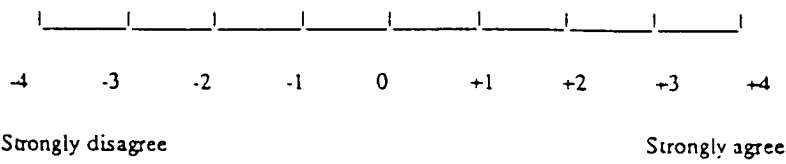
2. People make too much of the feelings and sensitivity of animals.



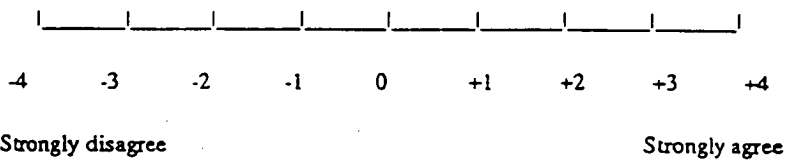
3. I often find public displays of affection annoying.



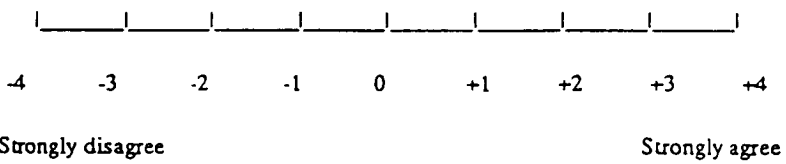
4. I get annoyed by unhappy people who are just sorry for themselves.



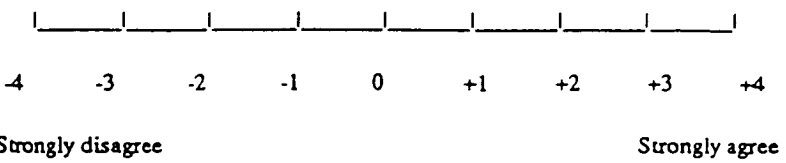
5. I become nervous if others around me seem to be nervous.



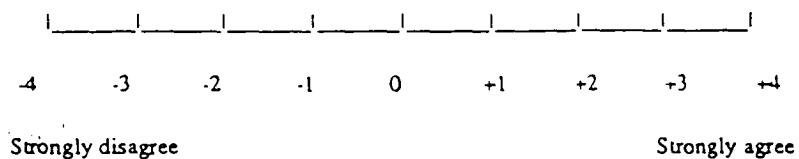
6. I find it silly for people to cry out of happiness.



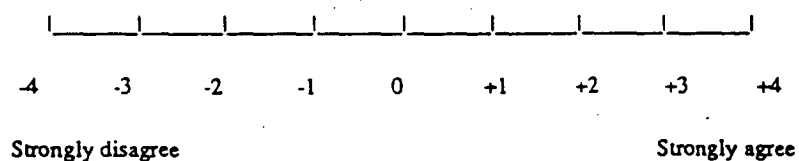
7. I tend to get emotionally involved with a friend's problems.



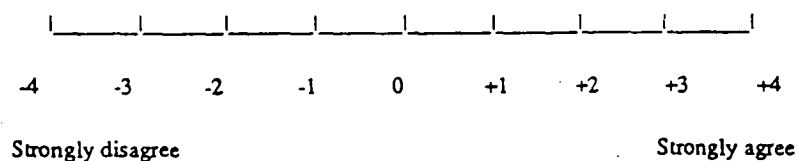
8. Sometimes the words of a love song can move me deeply.



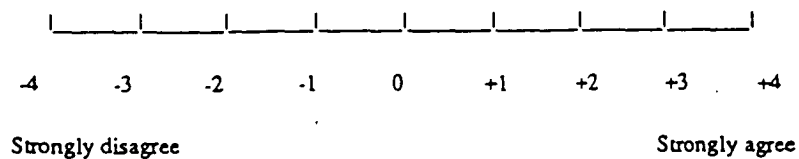
9. I tend to lose control when I am bringing bad news to people.



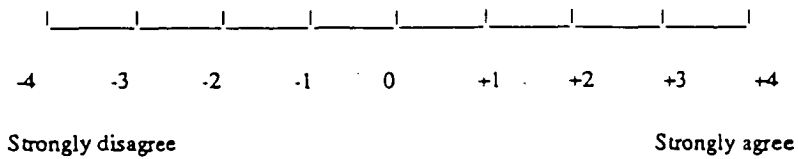
10. The people around me have a great influence on my moods.



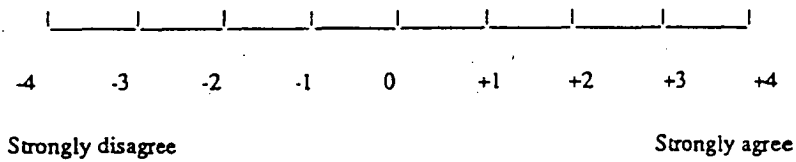
11. Most foreigners I have met seemed cool and unemotional.



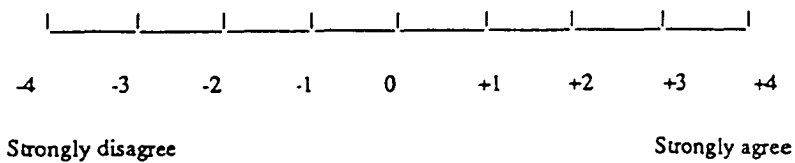
12. I would rather be a social worker than work in a job training centre.



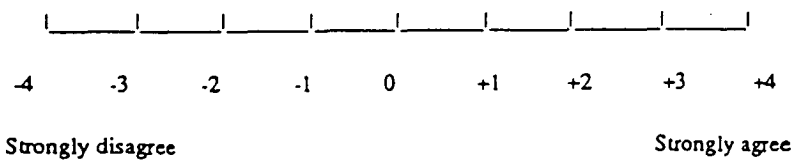
13. I don't get upset just because a friend is acting upset.



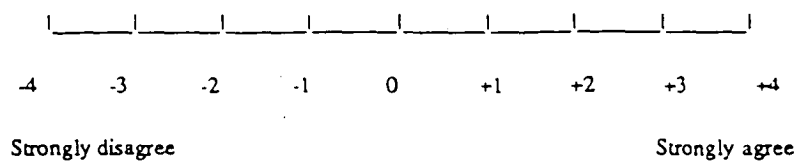
14. I like to watch people open presents.



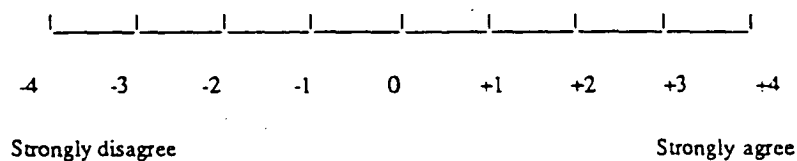
15. Lonely people are probably unfriendly.



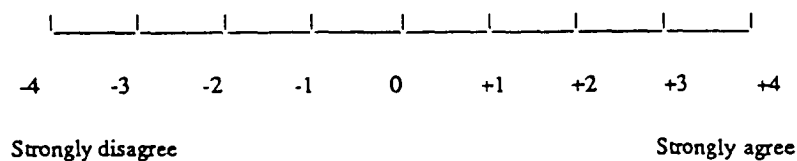
16. Seeing people cry upsets me.



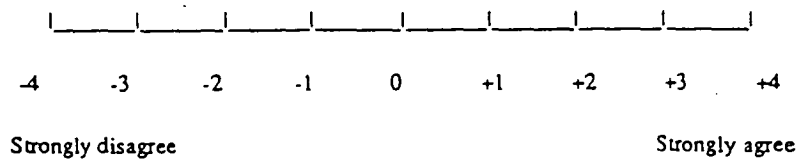
17. Some songs make me happy.



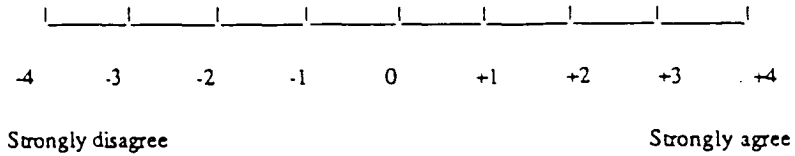
18. I really get involved with the feelings of the characters in a novel.



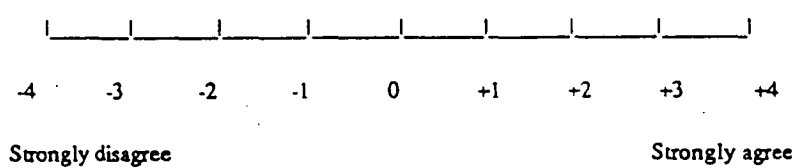
19. I get very angry when I see someone being ill-treated.



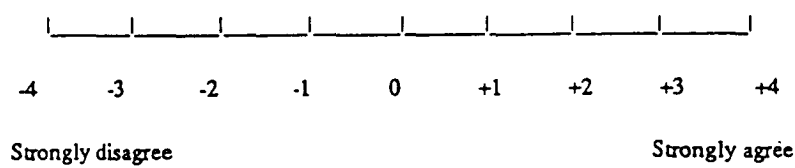
20. I am able to remain calm even though those around me worry.



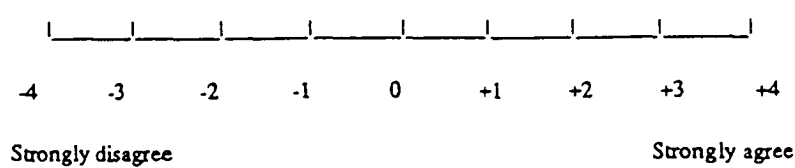
21. When a friend starts to talk about his problems, I try to steer the conversation to something else.



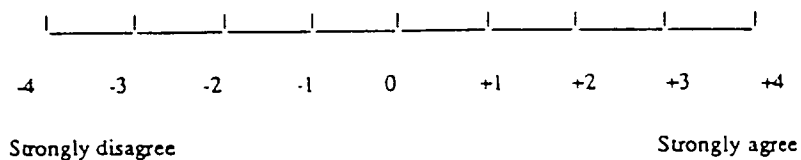
22. Another's laughter is not catching for me.



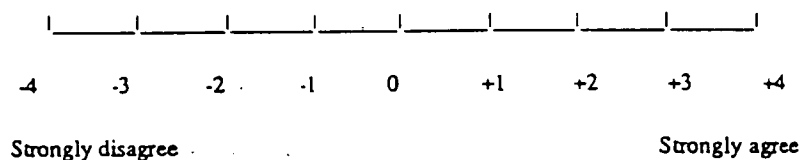
23. Sometimes at the movies I am amused by the amount of crying and sniffing around me.



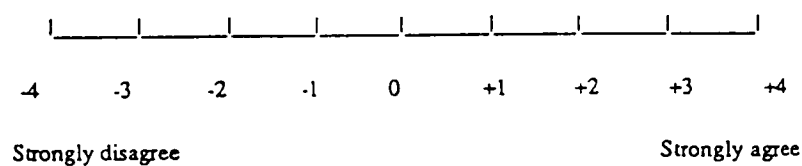
24. I am able to make decisions without being influenced by people's feelings.



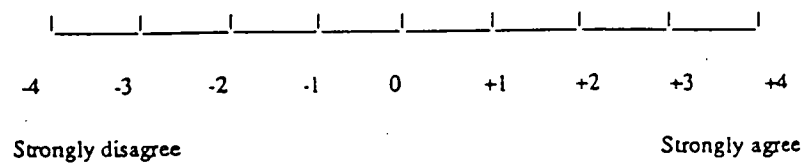
25. I cannot continue to feel OK if people around me are depressed.



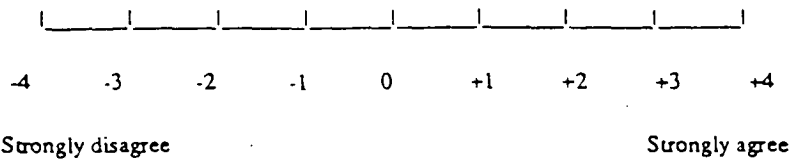
26. It is hard for me to see how some things upset people so much.



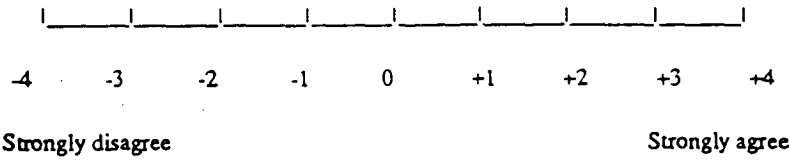
27. I am very upset when I see an animal in pain.



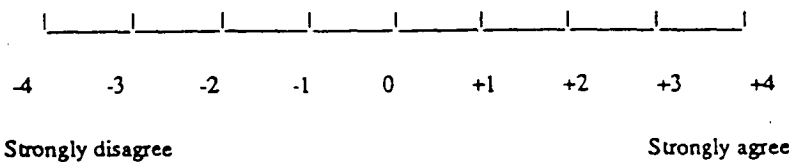
28. Becoming involved in books or movies is a little silly.



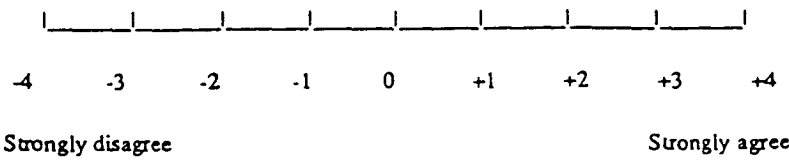
29. It upsets me to see helpless old people.



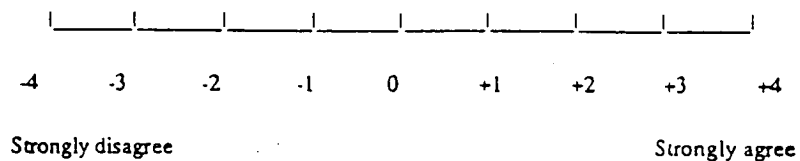
30. I become more irritated than sympathetic when I see someone's tears.



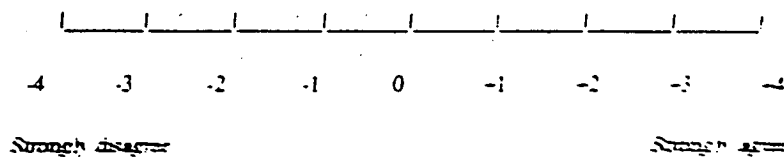
31. I become very involved when I watch a movie.



32. I often find that I can remain cool in spite of the excitement around me.



33. Little children sometimes cry for no apparent reason.



Appendix 3b.

Mean scores and standard deviations for MEEQ empathy ratings by proxies in Study 1.

Proxy Gender	<i>n</i>	<i>M</i>	<i>SD</i>	Range
Male	39	24.84	19.02	-17 to 58
Female	39	56.56	19.75	8 to 89
Total	78	44.30	25.58	-17 to 89

Mean scores and standard deviations for MEEQ empathy ratings by proxies in Study 2.

Proxy Gender	<i>n</i>	<i>M</i>	<i>SD</i>	Range
Male	3	31.00	18.36	10 to 44
Female	21	39.19	23.99	7 to 82
Total	24	38.17	23.19	7 to 82

Note : The following means and standard deviations for different genders are reported by Mehrabian and Epstein, 1972 for a study of $N = 202$: males, $M = 23$, $SD = 22$; and females, $M = 44$, $SD = 21$.

Appendix 4.

ANOVA Tables relating to Study 1.

Appendix 4a.

Main effects from ANOVAs on Concurrence Scores for Objective QOL for non-disabled subjects and their proxies.

Effect	<i>df</i>	<i>SS</i>	<i>F</i>	<i>p</i>
Proxy Empathy (a)	1,53	31.06	1.77	0.19
Proxy Relationship to Subject (b)	1,53	12.82	0.73	0.40
Proxy Living Arrangement in Relation to Subject (c)	1,53	00.01	0.01	0.99
Proxy Gender (d)	1,53	34.11	1.94	0.17
Proxy Gender in Relation to Subject Gender (e)	1,53	34.83	1.98	0.17

Note: (a) Proxy Empathy = high or low; (b) Proxy Relationship to Subject = parent or sibling; (c) Proxy Living Arrangements in Relation to Subject = with or separately; (d) Proxy Gender = male or female; (e) Proxy Gender in Relation to Subject Gender = same or opposite.

Appendix 4b.

Two-way interactions from ANOVAs on Concurrence Scores for Objective QOL for non-disabled subjects and their proxies.

Effect	df	SS	F	Sig.
Proxy Empathy x Proxy Relationship to Subject	1,53	65.57	3.73	0.06
Proxy Empathy x Proxy Living Arrangements in Relation to Subject	1,53	5.75	0.33	0.57
Proxy Empathy x Proxy Gender	1,53	50.48	2.87	0.10
Proxy Empathy x Proxy Gender in Relation to Subject Gender	1,53	4.50	0.26	0.62
Proxy Relationship to Subject x Proxy Living Arrangements in Relation to Subject	1,53	15.29	0.87	0.36
Proxy Relationship to Subject x Proxy Gender	1,53	59.02	3.36	0.07
Proxy Relationship to Subject x Proxy Gender in Relation to Subject Gender	1,53	3.68	0.21	0.65
Proxy Living Arrangements in Relation to Subject x Proxy Gender	1,53	6.21	0.35	0.56
Proxy Living Arrangements in Relation to Subject x Proxy Gender in Relation to Subject Gender	1,53	10.69	0.61	0.44
Proxy Gender x Proxy Gender in Relation to Subject Gender	1,53	10.71	0.61	0.44

Note: Proxy Empathy = high or low; Proxy Relationship to Subject = parent or sibling; Proxy Living Arrangements in Relation to Subject = with or separately; Proxy Gender = male or female; Proxy Gender in Relation to Subject Gender = same or opposite.

Appendix 4c.

Main effects from ANOVAs on Concurrence Scores for Subjective QOL for non-disabled subjects and their proxies.

Effect	<i>df</i>	<i>SS</i>	<i>F</i>	Sig.
Proxy Empathy (a)	1,53	44.92	0.22	0.64
Proxy Relationship to Subject (b)	1,53	28.62	0.14	0.71
Proxy Living Arrangement in Relation to Subject (c)	1,53	153.10	0.76	0.39
Proxy Gender (d)	1,53	0.07	0.01	0.99
Proxy Gender in Relation to Subject Gender (e)	1,53	427.99	2.12	0.15

Note: (a) Proxy Empathy = high or low; (b) Proxy Relationship to Subject = parent or sibling; (c) Proxy Living Arrangements in Relation to Subject = with or separately; (d) Proxy Gender = male or female; (e) Proxy Gender in Relation to Subject Gender = same or opposite.

Appendix 4d.

Two-way interactions from ANOVAs on Concurrence Scores for Subjective QOL for non-disabled subjects and their proxies.

Effect	df	SS	F	Sig.
Proxy Empathy x Proxy Relationship to Subject	1,53	13.23	0.07	0.36
Proxy Empathy x Proxy Living Arrangements in Relation to Subject	1,53	939.7	4.66	0.02
Proxy Empathy x Proxy Gender	1,53	1157.7	5.74	0.81
Proxy Empathy x Proxy Gender in Relation to Subject Gender	1,53	12.43	0.06	0.32
Proxy Relationship to Subject x Proxy Living Arrangements in Relation to Subject	1,53	201.28	1.00	0.32
Proxy Relationship to Subject x Proxy Gender	1,53	200.46	0.99	0.32
Proxy Relationship to Subject x Proxy Gender in Relation to Subject Gender	1,53	1051.8	5.21	0.03
Proxy Living Arrangements in Relation to Subject x Proxy Gender	1,53	44.98	0.22	0.64
Proxy Living Arrangements in Relation to Subject x Proxy Gender in Relation to Subject Gender	1,53	17.29	0.09	0.77
Proxy Gender x Proxy Gender in Relation to Subject Gender	1,53	1.62	0.01	0.93

Note: Proxy Empathy = high or low; Proxy Relationship to Subject = parent or sibling; Proxy Living Arrangements in Relation to Subject = with or separately; Proxy Gender = male or female; Proxy Gender in Relation to Subject Gender = same or opposite.